University of Alberta

# (Ad)ministering Love: Providing Family Foster Care to Infants With Prenatal Substance Exposure

by

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**Abstract**

Competent caregiving and early relationships are increasingly presented in the child development research literature as playing a major role in determining developmental outcomes for infants and children and as playing a significant role in enhancing the healthy physical, emotional, and social development of infants. Infants who have experienced prenatal substance exposure are frequently cared for within the environment of out-of-home care, or foster care; foster families are the primary caregivers within this system and therefore provide the environment and relationships key to supporting healthy development of infants already vulnerable due to multiple health and social challenges.

This qualitative research study identified the process of becoming a foster family and providing family foster care giving within the context of caring for infants with prenatal drug and alcohol exposure. A constructivist grounded theory approach was used to study foster families (including mothers, fathers, birth and adoptive children) who specialized in caring for infants within a Canadian provincial child welfare system.

The dissertation findings are presented in five sequential manuscripts. The basic social process for families caring for infants with prenatal substance exposure was identified as *(ad)ministering love*. This process represents the tension experienced by families that were committed to providing the love and guidance of a family to an infant with special needs, yet within the restrictions and public gaze of a government child protection system.

This theoretical framework explains and accounts for well-functioning family foster homes that care for infants with prenatal substance exposure and serves as a basis for improved practice, policy development, education and training, research and

evaluation. Information from this study will be useful for those interested in strengthening the system of foster care for the infant population, including health and social service providers who support infants and foster families, policy makers, particularly within the child welfare system, and foster families themselves.

**Acknowledgements**

Many years ago I made a promise to myself that I would begin my doctoral program when my youngest started school full time. In 2003 I walked my daughter to her Grade 1 class and then walked home and switched on the computer to begin my first semester of doctoral courses. As she worked her way through her grades, I worked my way through a thought provoking and challenging program. This year, Gillian* is finishing Grade 5 and I am finally finished my dissertation. It has certainly been a rewarding few years.

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**Table of Contents**

**Introduction** 15

Background to the Research 15

Purpose of the Study 17

Literature Review 17

Perinatal Substance Use 17

Medical Care of Infants With Prenatal Substance Exposure 20

Foster Families Who Care for Infants With Prenatal Substance Exposure 23

Research on Foster Parenting 27

Role of Health and Social Service Professionals 28

Overview of Manuscripts 30

Summary of Appended Materials 33

References 35

**Manuscript One:** Foster Families who Care for Infants with Prenatal Drug Exposure: Support During the Transition from NICU to Home 43

Evolution of the Role of Foster Parents 45

Current Issues for Foster Parents 47

Can we Apply the Postpartum Adaptation Literature to Foster Families? 49

Transition to Parenthood 49

Development of Maternal and Paternal Role Identity 51

Attachment 52

How Nurses can Support Foster Parents in the NICU 53

Working with Foster Parents in NICU Settings 53

Preparing for Transition to Home 54

Advocating for Support of Foster Families 56

Summary 58

References 59

**Manuscript Two:** Looking at Families in Nursing Research: Strategies for Study Design 73

A Good Starting Point: Defining Family and Family Nursing Research 75

Family 75

Family Nursing Research 76

Evolution of Family Research and Methodology 77

Developmental Theory 77

Structural-Functional 78

Systems Theory and Research 78

Relational Theory 79

Connecting Theory and Method: Conceptualizing a Family Research Study 80

Epistemologies 81

Theoretical Concepts 83

Research Methods 84

Sampling Process and Ethical Considerations 85

Data Analysis 88

Results Linkage 89

Summary 91

References 93

**Manuscript Three:** The Grounded Theory Method and Maternal-Infant Research and Practice 110

Looking Back at Qualitative Nursing Research 111

What is Grounded Theory 113

Key Components 114

Theoretical Sampling 115

Theoretical Sensitivity 116

Constant Comparison 117

Raising the Level of Abstraction 118

Identification of the Basic Social Process 120

Evaluation of the Quality of a Grounded Theory Study 121

Broadening the Scope of Grounded Theory: Synthesis 124

Using Grounded Theory in Practice: Relevance for Maternal-Infant Nursing 124

Summary 126

References 128

**Manuscript Four:** (Ad)ministering love: Providing family foster care to infants with prenatal substance exposure. 138

Context of the Study 139

The Changing Needs of Children in Foster Care 139

The Effects of Politics, Policy Shifts, and Media Representation on Child Welfare 140

and the Foster Care System 141

The Shifting Demographics of Foster Caregivers 143

Method 144

Theoretical Approach 144

Participants 145

Ethics Review, Consent Process and Confidentiality 147

Data Collection and Analysis 148

Rigor in the Study 149

Findings 150

Phase 1: Starting Out 151

Determining Family Readiness to Foster 151

Meeting the Requirements of the System 153

Immersing for the First Time and Finding Their Niche 154

Phase 2: Living as a Foster Family 157

Rebalancing Family Life With Each Placement 157

Honoring Limits 160

Experiencing an Emotional Double Bind 163

Working the Child Welfare System 166

Feeling a Powerless Responsibility 167

Public Parenting 168

Phase 3: Moving On 170

Relinquishing/Retiring from the Role of Foster Family 170

Losing Fit 171

Transferring Child Focus 172

Discussion 173

Fostering as a Social Justice Endeavor 173

Doing the Work 24/7 174

Unwitnessed Commitment 175

Implications for Practice and Research 176

Practice 176

Research 177

Limitations of Study 178

Conclusion 179

References 181

**Manuscript Five:** Supporting resilience in foster families: A model for program design that supports recruitment, retention and satisfaction of foster families who care for infants with prenatal substance exposure. 188

The Health and Social Needs of Infants in Foster Care 190

Foster Families Who Care for Infants with Prenatal Substance Exposure 192

Resilience as a Philosophy Underlying Foster Family Program Development 193

Resilience and Infants 194

An Infant Foster Family Care Model 196

Phase 1: Preparing to begin fostering 197

Phase 2: Living as a foster family 198

Phase 3: Ending fostering 199

Translation of the Infant Foster Care Model Within a Resiliency

Framework: 200

Knowing Caregiving Niche 201

Honoring Limits 202

Learning to Accept Emotional Double Bind 203

Feeling Powerless Responsibility 204

Living as a Public Parent 205

Implications of a Resiliency Framework for Foster Family 205

Summary 208

References 209

**General Discussion and Summary 220**

**Appendices 226**

**A:** Initial interview questions: time period 1 prior to beginning fostering

**B:** Initial interview questions: time period 2 within the first year of beginning fostering

**C:** Initial interview questions: time period 3 at least three years of fostering experience

**D:** Initial interview questions: resource workers

**E:** Information letter for foster families

**F:** Interview letter for resource workers

**G:** Consent form for foster families

**H:** Assent form for children in foster families

**I:** Consent form for resource workers

**J:** Recruitment criteria for participation

**List of Tables**


| | |
|---|---|
| Intro-1 | Current Position Statements and Clinical Guidelines Related to Perinatal Substance Use41 |
| 1-1 | Key Areas of Parent and Caregiver Teaching 65 |
| 1-2 | Suggestions for Foster Parents: Bringing Baby Home 67 |
| 1-3 | Suggestions for NICU Health Care Providers 72 |
| 2-1 | Selected Definitions of the Concept of Family 102 |
| 2-2 | Overview of Quantitative Data Analysis Approaches 106 |
| 3-1 | Examples of Basic Social (Psychological) Processes and Their Descriptions 133 |
| 4-1 | Motivations for fostering 186 |
| 4-2 | Reasons for leaving fostering 187 |
| 5-1 | Strategies to support foster families at different stages of development 215 |

## List of Figures


2-1 Connecting Theory and Method in Family Research 105

4-1 Infant Foster Family Model: (Ad)ministering Love 151

5-1 Infant Foster Family Model: (Ad)ministering Love 197

5-2 Interpretation of the Infant Foster Care Model from a Resiliency Perspective 201

## Introduction

The topic of this dissertation research is the exploration of how families provide foster care to infants with prenatal substance exposure. The research findings are presented using the mixed manuscript format option accepted by the Faculty of Graduate Studies and Research of the University of Alberta. This format consists of a series of published and yet to be published manuscripts describing the research. The manuscripts are preceded by this introductory section (consisting of an overview of the manuscripts) and followed by a general discussion and conclusion chapter.

## Background to the research

The increasing complexity and diversity of the needs of young infants and children coming into foster care is resulting in a requirement for more sophisticated expertise and a strengthened support system for foster parents. Research supports the notion that children with behaviors that are more difficult to manage have an undermining effect on parental functioning (Linares et al, 1999). A challenge within the foster system is to try to achieve "goodness of fit" between an infant with challenging behaviors and caregivers with the skills and resources to manage care of the infant within their family. An additional challenge in developing consistent responsive parenting in foster parents of infants with prenatal substance exposure is to effectively modify the usual parenting mechanisms to the needs of infants with challenging behaviors (such as irritability, and difficulty with feeding and sleeping) and to provide sufficient community support for both consistency and responsiveness to be maintained in the early care-giving environment.

The study of foster parenting is in general focused on global administrative issues such as recruitment, assessment, retention and support. There is limited scope to

the qualitative research available that focused specifically on the caregivers of infants, and on family members beyond mothers. The few studies that are available focus on task-based caregiving and the difficulties that foster parents have doing their work within the complexities of the child welfare system. There is scant representation of the type, quality and characteristics of the relationships that develop between infants and foster families.

Recent trends in the practice of child welfare have underscored the importance of examining infants as a unique population (Wulczyn et al., 2002). The large body of knowledge on infant development offers one framework for the study of the child welfare experiences of infants in foster care. For example, with older children, the policies and guidelines focus on issues such as management of behavior and support of emotions. With infants, the developmental equivalent is to have the focus on the responsiveness of the caregiver to the needs of the infants and the ability of the caregiver to accurately interpret the cues of the infant. A second intersecting body of knowledge on caregiving/parenting addresses the mediatory process that support of foster parents may have on the health and well being of infants.

The early care-giving environment for infants plays a critical role in their long-term health and development. Although children in foster care spend more time with foster parents than with any other representatives of the health or child welfare system, foster parents often are the least prepared for, and the least supported in, their responsibilities. There are currently only a small number of studies available that examine the process by which foster families take on the role of foster parent to at-risk infants. The perceived role ambiguity of foster parents created the need to study this process from the perspectives of both temporary caregiving and parenting.

***Purpose of the study***

The purpose of this study was to develop a grounded theory of foster family development related to identifying the process of becoming and providing family foster care for infants with prenatal substance exposure. Grounded theory, an inductive method of qualitative analysis that generates theory from data, provided a way to stay close to the experiences of individuals through their data and through situating meaning and interaction within the larger contexts of family, organization, community, and society. This study identified the basic social process through which foster families integrated this new knowledge and new skills and competencies into their family way of being, and the conditions that supported and hindered this development.

The research questions asked initially at the beginning of this study addressed the following: What is the basic social process through which foster families integrate the role of caring for infants with prenatal substance exposure into their ongoing family life? What are the conditions that support or hinder integration of this foster family role?

## Literature review

A comprehensive review of literature related to foster care of infants with prenatal substance exposure required critical examination of three interconnected areas of knowledge: a) perinatal substance use, b) medical care of infants with prenatal substance exposure, and c) characteristics and experiences of foster families who care for infants with prenatal substance exposure.

### Perinatal substance use

The care of women and newborns with prenatal drug and alcohol exposure has been widely recognized as a significant health problem in North America. In a national study in the United States, 4.3% of pregnant women reported using illicit drugs, 9.8%

used alcohol, and 18.0% used cigarettes during pregnancy (U.S. Department of Health and Human Services, 2003). In British Columbia, 12.4% of women reported drinking alcohol during their last pregnancy (BCRCP, 2006). The incidence is generally thought to be higher than reported because of the social stigma associated with alcohol and drug use during pregnancy and the fear of child apprehension; some women may have under-reported their consumption or not reported use at all during health care encounters or in social surveys (Willms, 2002). Contrary to assumptions that substance misuse is correlated with poverty and specific cultural groups, incidence studies have found that prenatal substance use is an issue for women from a wide range of socioeconomic and cultural backgrounds.

A best practices document by Health Canada (2000) summarizes that a range of harmful effects for both mother and child is associated with substance use during pregnancy. Fetal Alcohol Syndrome (FAS) is a medical diagnosis that refers to a set of alcohol-related disabilities associated with the use of alcohol during pregnancy, including growth restriction, central nervous system involvement, and/or characteristic facial features (Canadian Pediatric Society, 2001). FAS has been positioned as the leading cause of preventable birth defects and developmental delays in North America. Neonatal Abstinence Syndrome (NAS) is defined as a spectrum of withdrawal symptoms experienced by some infants exposed prenatally to opioids. Other substances, such as marijuana, cocaine, amphetamines, and prescription medications are also linked in varying degrees in the medical literature to fetal effects and compromised childhood outcomes.

First generation (or early) drug and alcohol research were based on simple effects models that examined direct effects of one suspected substance on specific aspects of

child outcome (Carta et al., 1997). In those studies, infants and children prenatally exposed to drugs and alcohol were identified as a high-risk group for developmental problems. However, few studies have examined these children's lives beyond the early years of life. First generation research has been criticized for using small convenience samples, using assessment methodologies which are not sensitive in identifying subtle or emergent effects, not addressing the issue of polydrug use, and failing to consider environmental factors (Lester, Andreozzi, & Appiah, 2004). The state of the literature itself has also been questioned by some researchers who found that early studies reporting no effects from cocaine exposure were less likely to be published than those that reported adverse outcomes (Koren, Graham, Shear, & Einerson, 1989).

Despite these limitations, the media trend has been to present generalized worst-case scenarios that have been negative in their accounts of substance-exposed infants and judgmental in their depiction of birth mothers (Boyd, 1999). In contrast to the general public's perception that illicit drugs are the most harmful for the developing fetus, it is the legal substances (alcohol and tobacco) that are associated in more recent research with a greater risk of harm.

The second generation of research has incorporated an expanded methodology for describing, assessing, and analyzing environmental and contextual factors in the lives of children and families. Jacobsen and Jacobsen (2001) suggest that bringing together two lines of research that reflect different perspectives on the effects of parental drug and alcohol use – the long-term effect of teratogenic insult due to prenatal exposure and the developmental risks associated with being reared by a substance-abusing parent, will offer a better understanding of the complex interrelated influences of risk factors on child development.

Beginning in the early 1990's, counterclaims began appearing about the extent and seriousness of the problems associated with prenatal substance exposure. Emerging literature, usually in other fields such as sociology, social work, psychology, and women's studies, but increasingly in the health care field, began to urge a more balanced and complex view of prenatal substance use. Evidence began to be offered that lifestyles associated with addiction, poverty, and lower levels of prenatal care may impinge on fetal development as much as drug exposure (Lester, Andreozzi, & Appiah, 2004; Lyons & Rittner, 1998). For example, Frank, Augustyn, Knight, Pell, and Zuckerman (2001), in their meta-analysis of studies examining outcomes of children exposed prenatally to cocaine, have concluded that maternal cocaine use should be recognized not as the sole cause of fetal insult, but as a "red flag" for the social and environmental variables associated with cocaine use that may adversely affect the health and well-being of the baby, regardless of their prenatal exposure. Despite what may be a move in the current scientific literature toward a more moderate position, disagreement among experts continues. The lack of consensus has contributed to confusion among the lay public, many of whom continue to be influenced by inflammatory assumption inherent in media reports on this issue (Ondersma, Malcoe, & Simpson, 2001).

***Medical care of infants with prenatal substance exposure***

NAS, although not a single pathological condition, is often treated as one entity (Theis, 1997). Originally conceptualized to reflect the physiological process of the infant reacting to the sudden unavailability of maternal opiates, a diagnosis of NAS is now commonly applied to infants exposed to and experiencing withdrawal from substances other than opiates. Some researchers suggest that polydrug use is now the norm, rather than the exception (D'Apolito & Hepworth, 2001; Greene & Goodman, 2003).

The responses to opiate withdrawal are similar to those in the adult, but because of the nature of neurological organization, the implications may be more severe in neonates (Blackburn, 2003). Recent literature states that NAS is found to occur in varying degrees in 48% to 94% of infants whose mothers used opiates during pregnancy (Osbourne & Cole, 2000). Withdrawal symptoms may develop in the first few days after birth or as late as two weeks after birth. Frequently seen symptoms include irritability, high-pitched cry, increased muscle tone, sleeping difficulties, feeding difficulties, and gastrointestinal dysfunction (American Academy of Pediatrics, 1998; Briggs, Freeman, & Yaffe, 2005; British Columbia Women's Health Centre, 2006). Withdrawal symptoms and the extent of withdrawal will also vary according to the amount and type of drug or drugs used (Greene & Goodman, 2003). In addition to withdrawal effects, infants whose mothers use opiates may also have specific risks related to injection drug use, personal health and social conditions, including HIV, Hepatitis C, SIDS, and low birth weight.

With NAS, the accepted goals of treatment are to provide comfort to the mother and infant in relieving symptoms, improve feeding and weight gain, prevent seizures, reduce unnecessary hospitalization, improve mother-infant interaction and reduce the incidence of infant mortality and abnormal neurodevelopment (American Academy of Pediatrics, 1998; Australian Ministerial Council on Drug Strategy, 2006; Osbourne & Cole, 2000). For many infants displaying mild, non-progressing symptoms of withdrawal, conservative management with strategies such as holding, swaddling and minimal stimulation is usually sufficient treatment (BCWHC, 2006; Theis, 1997). For infants with more severe symptomatology, pharmacological treatment may be required to stabilize the infant as far as physical dependence is concerned so that normal neonatal newborn patterns such as sleep and sucking can be restored, and severe effects such as

seizures and dehydration can be avoided. The American Academy of Pediatrics (1998) recommends that for infants with confirmed drug exposure the indications for drug therapy should be seizures, poor feeding, diarrhea and vomiting resulting in excessive weight loss and dehydration, inability to sleep and fever unrelated to infection.

Many aspects of perinatal care are routinely tracked by professional organizations, such as the American Academy of Pediatrics (AAP), the Association for Women's Health, Obstetrical, and Neonatal Nursing (AWHONN), the Canadian Institute of Child Health (CICH), and regional reproductive care programs. Most of these organizations have developed clinical practice standards related to perinatal care. Care of substance-exposed infants is also addressed in an increasing number of practice guidelines. Guidelines for practice are also increasingly found outside the nursing literature, including the areas of social work, addictions, and childcare. Table 1 identifies select current position statements or guidelines for practice related to perinatal substance abuse.

There has been little movement or advancement in the management of NAS since the initial reports in the 1970's. The early work of Loretta Finnegan and her research associates in Philadelphia continues to be upheld as the gold standard and as the theoretical background on which current studies and practice guidelines are designed (Finnegan et al., 1975). Most studies focus on pharmacological management as the primary mode of treatment and there is scarce evidence assessing the effectiveness of conservative management strategies of daily care (the work of nurses, parents, and alternate caregivers such as foster parents). Systematic research in infants in general has lagged considerably behind that for older children and adults, possibly for reasons such as the low level of status of infants in the social order or the ethical difficulties associated

with conducting research on this vulnerable population (Halstead et al., 2003; JAACAP, 2003; Merenstein & Glicken, 2002). It is also possible that continued research in the field of NAS lags even further behind as NAS does not have the "cachet" of other neonatal issues and is seen primarily as a social or moral issue.

Despite the withdrawal experienced in the first year of life, research studies indicate that these children do well if the mothers did not abuse other substances such as alcohol and if the children were raised in a supportive environment (Arendt et al., 2004; Marcellus & Kerns, 2007; Shankaran et al., 2007). There are still only a limited number of studies available which have studied the children into and beyond the school years. Some adverse effects noted by researchers include behavioural disturbances, brief attention span, temper outbursts, learning disabilities, delayed speech, and developmental delay. A 2006 evidence review by the National Abandoned Infants Assistance Resource Centre at the University of California-Berkeley summarizes that the effects of prenatal substance exposure (with the exception of alcohol) are not as profound as once believed. The review also suggested that both the direct biological effects of substance use and the postnatal effects of the environment (social determinants of health) overlap to produce a cumulative effect on health and developmental outcomes.

***Foster families who care for infants with prenatal substance exposure***

Foster parenting occurs in the midst of complex social, moral, systemic, and political contexts. Examination of the evolution of the role of foster parenting and trends in alternate care of children provides a basis for considering the current role that foster families play in the care of infants and children, and the supports and services that they need to do well in this role.

A review of literature related to development of foster care services reveals several consistent themes throughout the past 150 years within developing child welfare and foster care systems. Over time poverty has remained a central issue for families of children in care. Foster and Wright (2002) suggest that children in care continue to be from the poorest socio-economic groups in society, perpetuating the intergenerational effects of poverty, poor educational achievements, uncertain housing with frequent moves, earlier and longer episodes among the homeless population, and insecure parenting.

Minorities also continue to be over-represented in care. In British Columbia, for the last 30 years Aboriginal children have comprised at least one-third of the child-in-care population (Foster & Wright, 2002; Petch & Scarth, 1997). In 2000, 40.7 out of every 1,000 Aboriginal children were in care compared to only 7.2 per 1,000 for non-Aboriginal children. In the United States, children entering foster care are overwhelmingly African-American or of another minority (Barbell & Freundlich, 2001).

Finally, there has been a gradual heightening of societal expectations and standards for acceptable family functioning (Barbell & Freundlich, 2001). Cultural romanticizing of motherhood in North America has led society to expect nothing less than extraordinary mothers as normative (Cooey, 1999). Current standards of child rearing are based on visions of middle-class, white professionals and are then imposed on the realities of everyone else (Ashe, 1995).

Emerging trends which are currently being examined and implemented related to children-in-care include a return to kinship care (often grandparents), permanence planning, family preservation, professionalization of foster parents, consumer rights,

and acknowledgement of the necessity to address family and cultural diversity within service systems.

Despite ongoing attempts to reframe the philosophy and mandate of children's services, foster care continues to be the primary choice of method for caring for children removed from their families. There is an overwhelming amount of professional and public literature that presents concern about a crisis in foster care. A key issue identified is that the demand for foster homes is seen as outstripping resources. There are several contributing factors to this issue, including a decreased availability of traditional foster parents (mother at home), children requiring extended periods of time in care, increasing health and social needs of children in care, and political decision making which decreases supports to families already experiencing poverty and lack of services (Barbell & Freundlich, 2001).

The characteristics of infants and children in care have changed dramatically in the past 20 years. There has been an increase in both the number and intensity of health and emotional issues experienced by children in care. Foster parents in the past were expected to provide family-centered care within a home-like environment. Foster parents now deal with the continued expectation that they care for foster children with increasing needs, within a system that is slowly increasing licensing expectations, and within a society that is increasingly litigious and policy driven. At the same time as they try to manage budget cutbacks for basic programs and services children's ministries are feeling the pressure to conform to a number of well-meaning but restrictive and often conflicting recommendations from sources such as birth family advocacy groups, health associations, and children's commissions.

Reports written from the perspective of the foster family indicate that training and remuneration have not kept pace with the changes in their practice. Little or no compensation or training was thought to be required as the role was considered a form of volunteerism, and traditionally one taken on by women. It appears that a major issue related to support is the discordance between the work the foster parent is expected to do with the child and the amount of control the foster parent has over the situation and the amount of acknowledgement and respect they receive for their work (Wozniak, 2002).

A major issue is that foster parents who specialize in a particular population of children (for example infants with prenatal substance exposure) often end up having a stronger knowledge base than the professionals with whom they are working (Barton, 1998; Testa & Rolock, 1999). It has only been in the last 20 years that the need to train health professional in issues surrounding substance abuse has been recognized. Similar to the experiences of parents of children with chronic illnesses, health care systems and professionals often do not take into account this expertise developed by daily caregivers (Ray, 2003). Barton (1998) found that foster parents of cocaine-exposed infants reported that health care professionals often ignored their observations or concerns, and that their unique knowledge of the infant was often not taken into consideration. There are moves within the health system toward implementation of strategies such as philosophies of family-centered care and development of parent advisory councils to improve the parent's role in the care of their child, but the major difference between parents of children with chronic illness and foster parents is that the foster parents do not have legal guardianship and have an even more limited ability to advocate for their foster children.

In summary, a primary challenge is to develop services which meet the needs of the primary clients (infants and their foster caregivers), address recent best practice research, meet policy requirements, and are flexible enough to adapt to a range of community situations. Few communities have developed programs related to education and support of foster parents caring for infants with prenatal substance-exposure despite the number of infants requiring specialized foster care (Burry, 1999; Marcellus, 2002; Zukoski, 1999).

***Research on foster parenting***

Research of children in foster care is challenging to conduct and researchers have reported many methodological difficulties in designing and implementing studies (Flynn & Bouchard, 2005). Some of the main issues identified previously in the literature include the use of small convenience sample sizes, little use of standardized instruments (and instruments that have not been normed on a foster care population), inadequate consideration of numerous confounding variables, difficulty comparing statistics due to different data collection systems, and difficulty with longitudinal studies because of the transitional nature of children's care. The result was that child welfare research tended to be non-cumulative and contained few longitudinal and intervention studies. However, in the past ten years, research in this field has developed substantially.

An overview of existing research on foster parenting reveals research issues similar to that of research of children in foster care. There has also been an increasing interest in research related to the recruitment and retention of foster families. Even though a heavy focus of studies is recruitment and retention, a smaller number of studies have examined issues of significance to the daily practice of a foster parent, such as making parent visits more successful and dealing with grief and loss. Information

about foster parents is often indirectly studied as a part of outcome studies of children in care or as contributing to an intervention for children in care. Interestingly, Brown and Calder (2000) state that the needs of foster parents are well researched and are well known, but despite that no one has been creating interventions or services which address them (for example the need for respite services).

***The role of health and social service professionals***

Professionals working within health and child welfare systems often report feeling overwhelmed by the complexity of the lives of mothers with substance issues. Balancing child protection and family preservation, and maximizing positive outcomes for children, is a difficult and complex task. Most child welfare agencies currently agree that as long as the child's safety and well being can be assured, a child's family is the preferred environment for the child's care and upbringing (B.C. Ministry for Children and Families, 1998). Non-voluntary public involvement in family life (whether by removing a child from the home or mandating specific social services) is seen as an intrusion and as a last resort. It is viewed as appropriate only when a family is judged to have failed in its basic child-rearing responsibilities, a judgment that is often complicated by bias to race, ethnicity, class, and gender. In many cases, even though not stated in policy, many health and child welfare practitioners consider prenatal substance exposure a form of child abuse (Noble, 1997). There is often profound disagreement among professionals regarding substance use itself and its effect on the ability to parent (Ondersma, Malcoe, & Simpson, 2001).

Current child welfare policies are legislated to make reasonable efforts to support families and to keep them together, but they are also required through law to protect children from harm and ensure their safety. It is often a constant struggle for

child welfare professionals to manage the tension of the dual responsibilities. When substance use enters the picture, this mandate becomes difficult to balance, for the cycle of recovery does not always mesh with the child's needs or the timelines for child welfare decision making. To complicate matters further, these mandates must be met within an under-funded system where families needs often extend far beyond the scope of what service providers can offer. Although parental substance abuse should be of concern in assessing risk for child abuse or neglect, it is often not viewed within an overall context of risk. Other factors, such as the availability of other caregivers, parenting skills, the parent-child relationship, and family resources and supports are often discounted because of the hysteria and stereotypes that surround substance-abusing parents, particularly mothers.

The health of children in foster care and the well being of foster families are practice issues where ownership lies between two complex systems – the health care system and the child welfare system. Traditionally, the two systems have not had extensive connections. With the increasing health needs of children in care, there is a greater need to develop services that work in this interface. Linking services requires that professionals become more aware of the practice philosophies and priorities of other disciplines as they are often different and result in competing interests being represented within the plan of care for the child. The current restructuring that is occurring in provinces across Canada within both the child welfare and the health systems provides timely opportunities to create new ways of providing support and education to children in foster care and their caregivers.

## Overview of Manuscripts

The results of the study are presented in five manuscripts. As this is a mixed manuscript format dissertation, each chapter (excluding this introductory and final chapter) is a manuscript appropriate for publication. Since this research has practice and policy implications for both health and social service disciplines, the manuscript styles vary to meet the needs of these groups.

- Manuscript 1 provides a review of the literature regarding support of foster parents who are caring for infants with prenatal substance exposure for a neonatal nursing audience;
- Manuscript 2 describes the applicability of the grounded theory method for research in the maternal-infant nursing field;
- Manuscript 3 explores issues related to use of the family as the unit of analysis for researchers and practitioners in the field of maternal-child and family health;
- Manuscript 4 presents the findings of the grounded theory study for practitioners and researchers; and
- Manuscript 5 interprets the study results within a resilience framework and from a social work and child protection perspective.

***Manuscript 1***

This manuscript has been published: Marcellus, L. (2004). **Foster parents who care for infants with prenatal drug exposure: Support during transition from NICU to home.** *Neonatal Network,* 23(6), 33-42.

Infants exposed prenatally to drugs and alcohol tend to enter the child welfare system at a younger age and often directly from the hospital following birth. This article examines three concepts from the postpartum family adaptation literature (transition to

parenthood, maternal and paternal role identity, and attachment) and applies them to the experiences of foster parents who care for infants with prenatal drug and alcohol exposure. Recommendations are reviewed for development of strategies that promote development of the foster parent-infant relationship and parental knowledge within the NICU setting and during the period of transition from hospital to home. Nurses within the NICU have a unique knowledge of and experience with caring for infants experiencing withdrawal. This knowledge needs to be shared beyond the hospital with community professionals who often may have limited training in infant health, mental health, or development.

***Manuscript 2***

This manuscript has been published: Marcellus, L. (2007). **Looking at families in nursing research: Strategies for study design.** *Issues in Comprehensive Pediatric Nursing, 29*(4), 225-245.

Pediatric nurses have identified the importance of studying children within the context of their families. There have been calls for attention to the family as the focus of study and the unit of analysis in nursing research. One of the most important strategies for designing a study that keeps the focus on the family is the maintenance of study integrity. All the strategic choices made by the researcher when developing the research design need to reflect the theoretical premises on which the study is built. Throughout the study design, components of a well-constructed family research will demonstrate consistency with the overall conceptual framework.

***Manuscript 3***

This manuscript has been published: Marcellus, L. (2006). **Grounded theory methodology and maternal-infant research and practice.** *Journal of Obstetric,*

*Gynecologic, and Neonatal Nursing, 34*(3), 349-357.

Perinatal nurses have found qualitative methods helpful in capturing the social, cultural, and relational aspects of their work with women and their families. The purpose of this article is to describe the components of the grounded theory method and illustrate each with examples from recent maternal-infant studies. Grounded theory is an inductive method of qualitative analysis that generates theory from data. The grounded theory method includes several key strategies such as theoretical sensitivity, theoretical sampling, constant comparison, increasingly abstract consideration of the data, and discovery of a core variable or basic social process that describes the pattern of the phenomenon under study. This method may be a way to increase the strength of qualitative nursing studies because of its generalizability and applicability across settings. By remaining grounded in and connected to the data, grounded theory has the ability to be adapted to many contexts, making it useful to the practicing nurse. Knowledge generated from grounded theory has great potential to assist us in our inquiry into the needs of mothers, fathers, infants, and their families.

***Manuscript 4***

This manuscript has been submitted for publication. Marcellus, L. (submitted). **(Ad)ministering love: Providing family foster care to infants with prenatal substance exposure.** Qualitative Health Research.

A significant percentage of children in foster care in North America are less than one year of age and are in foster care because of parental substance use and other social challenges. Infants may present with specific health and behavioral issues that are challenging to manage within the foster family home environment; foster families require specialized skills and knowledge to manage these issues. This article describes a

constructivist grounded theory of the process of becoming and providing family foster care giving in the context of caring for infants with prenatal alcohol and/or drug exposure. The basic social process of *(ad)ministering love* was identified. This article describes the three phases of this process and the core concepts within each phase. Recommendations for practice and research are described.

***Manuscript 5***

This manuscript has been submitted for publication. Marcellus, L. (submitted). **Supporting resilience in foster families: A model for program design that supports recruitment, retention and satisfaction of foster families who care for infants with prenatal substance exposure.** Child Welfare.

As the health, social and developmental needs of children in foster care become more complex, foster families are challenged to develop specialized knowledge to effectively address these needs. Resilience theory provides a useful framework for describing strategies that have the potential to strengthen recruitment and retention of foster families and to increase the satisfaction of families providing foster care. This article describes an infant foster care model, applies resilience theory to the model and provides recommendations for program development for foster families that specialize in the infant population.

**Summary of appended materials.**

Because the manuscripts were tailored for publication, many of the supportive documents usually available in dissertations are not available within the manuscripts themselves. Appended documents such as interview questions, consent forms and participant information forms are included. In addition to study documents, the following additional dissemination resources are also included:

**A:** Initial interview questions: time period 1 prior to beginning fostering

**B:** Initial interview questions: time period 2 within the first year of beginning fostering

**C:** Initial interview questions: time period 3 at least three years of fostering experience

**D:** Initial interview questions: resource workers

**E:** Information letter for foster families

**F:** Interview letter for resource workers

**G:** Consent form for foster families

**H:** Assent form for children in foster families

**I:** Consent form for resource workers

**J:** Recruitment criteria for participation

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**Table 1**

**Current position statements and clinical practice guidelines related to perinatal substance use**

| TITLE | ASSOCIATION |
|---|---|
| Improving treatment for drug-exposed infants | Treatment Improvement Protocol Series (#5) Center for Substance Abuse Treatment U.S. Department of Health and Human Services (1993) |
| Substance use guidelines | British Columbia Reproductive Care Program, Vancouver, British Columbia November (1999) |
| Protecting children in substance-abusing families | National Center on Child Abuse and Neglect, U.S. Department of Health and Human Services (1994) |
| Neonatal drug withdrawal | Committee on Drugs, American Academy of Pediatrics, 1995 |
| Drug-exposed infants | Committee on Substance Abuse American Academy of Pediatrics (1996) |
| Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects in Canada | Canadian Pediatric Society and 17 other cosignatories (1997) |
| Guidelines for perinatal care | American Academy of Pediatrics and American College of Obstetricians and |

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|---|---|
| | Gynecologists (1997) |
| National clinical guidelines for the management of drug use during pregnancy, birth and the early development years of the newborn. | Australian Ministerial Council on Drug Strategy (2006). |
| Pregnancy Related Issues in the Management of Addictions (PRIMA). | University of Toronto (2005). |
| Integrated care pathways guide 8: Drug misuse in pregnancy and reproductive health. | Scottish Executive - Effective Interventions Unit (2004). |
| Practice guideline: Management of perinatal substance use and abuse. | Child Health Network for the Greater Toronto Area (2002). |
| Neonatal abstinence syndrome guidelines. | New South Wales Health (2002). |

**PAPER 1**

**Marcellus, L. (2004). Foster parents who care for infants with prenatal drug exposure: Support during transition from NICU to home. *Neonatal Network, 23*(6), 33-42.**

**(This manuscript was a recipient of one of three 2004 writing awards for this journal)**

## PAPER 1

### Foster Families Who Care for Infants With Prenatal Drug Exposure: Support During the Transition from NICU to Home

Don arrives at the hospital carrying the new car seat and a bag with a beautiful little outfit for the new baby. He meets Carol in the nursery with great excitement and they get their tiny baby all dressed for discharge. But first they gather their belongings and walk over to the social worker's office. Don and Carol are foster parents and they are here to attend a discharge meeting with the community team and the birth parents before they take the baby home.

Throughout the perinatal and neonatal literature there is increasing mention of alternate family formations. Blackwell and Blackwell (1999) state that the number of traditional families appears to be declining and the number of alternative families seems to be rising. Foster families are one form of alternate family formation that are dedicated to caring for some of our most difficult to care for infants. They often receive little recognition or respect for the committed work that they do within their communities, despite the fact that they care for a significant number of infants and children with increased health and social risk factors.

In the United States in 2000, it was estimated that there were approximately 588,000 children in foster care (Administration for Children and Families, 2003). Of that number, approximately one in four children were under 5 years old, with infants and toddlers being the most rapidly expanding age group in the child welfare system (Dicker, Gordon, & Knitzer, 2001). Infants exposed prenatally to drugs and alcohol tend to enter the child welfare system at a younger age and often directly from the hospital following birth (Frame, 2002; Wulczyn, Hislop, & Harden, 2002). The relationship

between infant and foster parent is therefore often initiated within the neonatal intensive care unit (NICU) setting. The frequently prolonged hospital stays for infants with prenatal drug and alcohol exposure provide an ideal opportunity for teaching, for caregivers to begin to understand and interpret the behavior of the infant, and for arrangement of needed community supports and resources.

In this article, evolution of the role of foster parenting will be reviewed and their role in caring for at-risk infants discussed. The process of how foster parents incorporate infants into their family life will be contrasted to the prevailing literature on transition to parenthood, maternal role identity and attachment. Suggestions are provided for promoting support of foster parents within the NICU setting and throughout transition to home of the infant.

**Evolution of the Role of Foster Parents**

The idea of substitute care for infants and children is not new and has been around as long as social groups, particularly many years ago when mortality rates for women in childbirth were high and life spans were short. Also, depending on the cultural group, different caretaking arrangements have existed for the care of children and other family members such as the elderly. The notion of contemporary child welfare began at the time when the unique nature of childhood emerged as a concept, essentially the past 150 years (Smith & Merkel-Holguin, 1996). Before that time, children were seen as property or as small adults expected to contribute to the well being of the household; the working child was seen often as a necessary means toward maintaining financial survival of a household (Hacsi, 1995).

In eighteenth century Europe, the almshouse was seen as economical way of gathering together stray humans unable to defend for themselves, and stranded children

whose parents were unable or unwilling to care for them (Folks, 1902). Almshouses were developed in North America particularly in response to waves of immigration in larger cities (English, 1984). Children were housed with "criminal, insane, and diseased" adults, and experienced high rates of mortality. The plight of unwanted children was often similar to that of the sick or deformed child, and the development of institutions specifically for the care of children began; the primary motivation for the creation of orphanages was to remove children from the almshouses and create an environment more suitable for childrearing. However, a chief complaint of orphanages was that rather than supporting childhood they often ended up stifling it. For infants, their health conditions and mortality rates actually worsened within the orphanages (Folks, 1902). For abandoned infants in the numerous orphanages of the day, mortality rates reached 97% as late as 1850 (Mahnke, 2000). Three related health problems - inadequate nutrition, recurrent epidemics (such as purulent opthalmia neonatorum, diphtheria, diarrhea, respiratory infections, measles, tuberculosis), and difficulty in providing sufficient nurturing – made a less than satisfactory environment for children. Abraham Jacobi, considered the founder of the American Academy of Pediatrics, suggested that 19th century medicine could not solve the health problems presented by large institutions: "the younger the child, the larger the institution, the surer is death" (in Mahnke, 2000, p. 710), and he suggested looking at other solutions, such as boarding out children in country homes or foster care, also called "in nurse" (Folks, 1902).

In addition to orphanages, children were indentured to families as servants or apprenticed to learn a skill and pay for their care by providing free labor. Indenture and adoption following time in an orphan asylum was frequently seen as a method of disposing of older wards. As big industrial cities were seen as inappropriate places for

children to be raised, large numbers of children were sent to families in the countryside. Thousands of children were sent via the "orphan trains" from Britain to Canada, and from cities such as New York City to the Midwest, where they were placed with families (Hacsi, 1995). The volunteer families may have been interested in providing a good home but often they were primarily interested in the free labor.

Foster care, sometimes called boarding out, emerged in response to the critiques of institutionalized care of children and the "free labor" mentality of indenture. Foster families were offered payments in lieu of the free labor and agencies began to be more careful about the homes they chose. The growth of foster care has been tied to increasing involvement of government, emergence of the juvenile court system, and an increased societal awareness of the rights of children and the social issue of child abuse and neglect (Schene, 1998).

**Current issues for foster parents**

In the United States today, there are over 133,000 foster families caring for approximately 588,000 children (Administration for Children and Families, 2003). Historically, women have traditionally been the primary caregiver, and often in a volunteer capacity. One reason that the child welfare system has been experiencing a shortage of qualified foster families is that women have been increasingly moving to out-of-home employment (Kelso, 1998). There has also been a sharp increase in the number of kinship (related to the infant) caregivers who are assuming custody and full time care of the infant. Kinship caregivers are often grandmothers who are parenting their grandchildren (Gleeson, O'Donnell, & Bonecutter, 1997; Hagar & Scanapieco, 1999).

The characteristics of infants and children in care have changed dramatically in the past 20 years. There has been an increase in both the number and intensity of health

and emotional issues experienced by children in care. Many children now entering foster care have been severely traumatized and have special medical, psychological, and social needs that traditional child welfare and foster care services were not designed to address (Rosenfeld et al., 1997). Research has consistently shown that children receiving foster care in general have an increased incidence of chronic medical conditions and a lack of general health care and developmental and mental health monitoring (Committee on Early Childhood, Adoption, and Dependent Care, American Academy of Pediatrics, 2002; Halfon, Mendonca, & Berkowitz, 1995; Kools, & Kennedy, 2003). The Child Welfare League of America (1988) has coined the term "new morbidities" to reflect the health outcomes that result in children exposed to environmental factors such as poverty, violence, and substance use.

Infants are at risk of development of a constellation of health issues specific to their developmental age. They are more vulnerable to the effects of malnutrition, physical abuse, and emotional deprivation than any other age group as these all have the potential to impede physical development and brain growth (Silver et al., 1999a). Clyman, Harden, and Little (2002) suggest that as many as 75% of young children in foster care placement need further developmental evaluation or have a developmental delay. In centers that assess and treat foster children, one of their primary populations is that of the young infant or child who has experienced prenatal substance exposure, and parental neglect or abandonment often associated with parental drug and/or alcohol use. Frequently noted health issues for infants include drug and alcohol exposure, risk of exposure to infectious diseases, failure to thrive, poor weight gain, prematurity, feeding problems, developmental delays, immunization delays, upper respiratory illnesses, and skin conditions (Silver et al., 1999b).

Foster parents often specialize in caring for specific age groups of children and develop a high level of expertise in the type of care needed. Similar to the experiences of parents of children with chronic illnesses, health care systems and professionals often do not take into account this expertise developed by daily caregivers. Barton (1998) found that foster parents of cocaine-exposed infants reported that health care professionals often ignored their observations or concerns, and that their unique knowledge of the infant was often not taken into consideration. A major difference between birth parents and foster parents is that the foster parents do not have legal guardianship and do not have access to full health information about the infant, so they have a more limited ability to advocate for their foster children (Ross & Crawford, 1999).

**Can we apply the postpartum family adaptation literature to foster families?**

Most of the literature on postpartum family adaptation is focused on first time biological parents, and often with families within relatively favorable socioeconomic and relationship circumstances (Cowan & Cowan, 1995). In this next section, three frequently researched concepts related to postpartum family adaptation will be briefly reviewed and applied to foster parenting of the infant.

***Transition to parenthood***

Transition to parenthood is one of the most extensively studied concepts in parent-infant nursing. In general, studies show that new parents experience shifts in the quality of their relationship with each other and with the infant, in their balance between support and stress, and with personal well being (Belsky & Rovine, 1990). Cowan and Cowan (1995) state that most research on transition to parenthood concludes that it constitutes a period of stressful and sometimes maladaptive change for a high percentage (up to 90%) of new parents. Following childbirth, parents are expected to

integrate a new family member, reorganize their lifestyle, reassess their role as spouses or partners, and maintain an environment which meets their own needs and those of their other children (Michaels & Goldberg, 1988; White & Booth, 1985).

There are few studies of transition to parenthood for non-biological parents. Levy-Shiff, Goldshmidt, and Har-Even (1991) studied the responses of adoptive parents to the arrival of their first child and reported that they had more positive expectations and more satisfying experiences in their transition to parenthood than biological families. They suggested that there might be a different underlying process. Stressors included a more abrupt involvement with the infant with no gradual involvement in the parental role, a parenting status that is not fully secured at the arrival of the child, and not being present during the immediate post-delivery contact stage, thought to be critically important for maternal-infant attachment. Strengths included an older average age of parents and a greater likelihood of marital stability, financial security, and greater mutual understanding.

The process of transition to parenthood for foster parents is unknown. Stressors for foster parents include an abrupt involvement with an infant (similar to adoptive parents), limited opportunity to gain knowledge of the infant prior to initiation of the relationship, the presence of birth parents, the expectation of being a caregiver versus a parent, and the inability to assume full legal responsibility for the infant. An additional systemic stressor for foster parents is that of working within the complexity of the child welfare system.

Silver et al (1999a) state that the role of foster parents is ambiguous – are they surrogate parents or are they employees of the child welfare agency? Historically foster parents have been viewed as temporary caregivers or babysitters; children have

generally been placed and removed from foster parents' care with little regard to the caregivers rights or feelings about the children (Barbell & Freundlich, 2001). However, 64% of the adoptions of children in foster care in 1999 were by the children's former foster parents (U.S. Department of Health and Human Services, 2000). Foster parents experience the challenge of being expected to develop attachment with the infant and yet be prepared to return the infant to their birth families and potentially not see the infant again; they place themselves and their emotions at risk when they bond to an infant, but they place the infant at risk if they do not (Edelstein, Burge, & Waterman, 2001).

***Development of maternal and paternal role identity***

Mercer (1995) describes acquisition of the maternal role as a staged process that occurs gradually over the infant's first year of life. Developmental models of maternal adaptation to pregnancy describe maternal and paternal tasks of pregnancy, including establishing a relationship with the unborn child, preparing for early parenthood, and adjusting to changes in self and the couple relationship (Martell, 2001; Mercer, 1995; Rogan, Shmied, Barclay, Everitt, & Wyllie, 1997; Walker, 1986).

The majority of foster parents who care for infants have had previous experience as parents and take on the role of foster parent with some confidence in their parenting abilities and with an existing identity as parent. Those foster parents who are new to the role will have had their identity as parents shaped by their experiences with usually healthy infants. A challenge for the foster parent is to adapt their parenting frames of reference to include seeing themselves as parents or caregivers of infants with special needs, and also to coping with abrupt taking on and letting go of their parenting role with specific infants.

Nelson's (2002) meta-analysis of qualitative studies that examined the process of mothering other-than-normal children provides some insight into this reframing of parenting identity. The work of learning how to mother a special needs child was termed "reconstruction" by several researchers. Somewhere in this process of negotiating a new kind of mothering, the mothers had to restructure their maternal image to accommodate their new role as the mother of an atypical child. They devised unique ways to communicate with their children and reported a particular intensity in the mother/child relationship due to their child's dependency. Similarly, Miles, Holditch-Davis, Burchinal, and Nelson (1999) studied the mothers of medically fragile infants and found that they experienced both stress and personal growth as a result of their child's illness. They suggest that struggling through a significant life event such as illness of a child requires parents to revise and rebuild their schemas about life in a way that makes the stressors seem more understandable and meaningful.

***Attachment***

Attachment is defined as the "deep and enduring connection established between a child and caregiver in the first several years of life" (Levy & Orlans, 1998, p. 1). The process of attachment is considered a mutual regulatory system, where the baby and the caregiver influence each other over time (Crockenberg & Leerkes, 2000; Goulet, Bell, St-Cyr Tribble, Paul, & Lang, 1998). This infant and mother relationship is seen as critical for healthy psychological and social development. Levy and Orlans (1998) suggest that attachment is developed within the context of a relationship that includes factors such as nurturing touch, safe holding, eye contact, smile, positive affect, and need fulfillment. For infants with prenatal substance exposure, these factors may be difficult to achieve in the early neonatal period. The stress of withdrawal makes it

difficult for the infant to manage the stimulation associated with touch and eye contact. Need fulfillment and engagement may be difficult to achieve with an infant that is experiencing the discomfort of withdrawal and with an infant that may give ambiguous cues and have disorganized behavior (Blackburn, 2003; Crockenberg & Leerkes, 2000).

An issue identified in many references is the incompatibility between the experience of frequent foster home placement changes for infants and the need for those infants to develop secure attachments (Morrison, Frank, Holland, & Kates, 1999; Stovall & Dozier, 1998; Wulczyn, Hislop, & Harden, 2002). Bishop et al. (2001) studied a sample of juvenile court records and reported that over half of the infants in their study experienced multiple placements during their time within the child welfare system. A study by Stovall and Dozier (2000) of infants in foster care found that attachment with foster mothers took from 2 weeks to 2 months to stabilize in infants. The implication of these studies is that infants in foster care often may not be given the opportunity to develop an enduring relationship with a consistent caregiver.

## How nurses can support foster parents in the NICU

Interpretation of the postpartum family adaptation literature from perspective of foster parents provides clear direction for development of strategies to promote development of the parent-infant relationship and parental knowledge within the NICU setting and during the period of transition from hospital to home.

### *Working with foster parents within the NICU setting*

In many hospital settings, foster parents do not have any contact with the infant until just prior to discharge (Marcellus, 2002) and there is little opportunity for parent teaching or for the foster parent to begin to understand the cues and behaviors of the infant. Infants who have experienced prenatal substance exposure may have many

behavioral issues, including feeding difficulties, irritability and difficulty with settling, and sleeping difficulties. It is important for the caregivers of the infant to have an opportunity to visit and establish a relationship prior to discharge. Similar to parents of premature infants who have been in the NICU for a prolonged time, foster parents of infants with prenatal substance exposure who visit frequently will become more aware of the infant's patterns of behavior than the staff nurse who may only be caring for the infant for a few shifts. Foster parents are able to contribute to decision-making about issues such as feeding techniques and determination of an appropriate level of environmental stimulation. Additionally, having the foster parent visit in the hospital provides an opportunity for them to initially meet with the birth family in a neutral setting.

When foster parents are visiting in the hospital it is important to maintain confidentiality, particularly if there is a history of violence with the birth parents. Last names and phone numbers should not be placed on the Kardex or in the front of the chart where they may be seen by the birth family. Some birth families may not be emotionally ready to meet the foster family, and then it is important for the nurse to schedule visiting times for the birth and foster families to avoid contact.

***Preparing for transition to home***

Discharge planning is a critical component of successfully transitioning the infant to the community from the NICU. Most guidelines related to discharge of high-risk infants suggest that the needs of this population are best met by an interdisciplinary team (American Academy of Pediatrics, 1998; Thompson, 1993; U.S. Department of Health and Human Services, 1993). An important relationship to develop is the one between NICU staff and social workers with the children's ministry or agency

responsible for child protection. A challenge within the health and child welfare systems is to try to achieve "goodness of fit" between an infant with challenging behaviors and a parent or alternate caregiver with the skills and resources to manage care of the infant within their family. Nurses play a key role in providing team members with a clear picture of the daily care needs of the infant. Knowledge of the infant's likes and dislikes and the intensity of their symptoms is important in designation of a foster home where the caregivers have adequate skills and resources to successfully care for and support the infant.

Many neonatal intensive care units have developed clinical practice guidelines specific to the infant with prenatal substance exposure. Planning for transition to home is considered within most of these guidelines (Marcellus, 2002). Key areas within clinical practice guidelines include criteria for discharge, discussion of the home plan for care, post-discharge follow-up recommendations, and links to children's services and early intervention.

The Association for Women's Health, Obstetric, and Neonatal Nursing (AWHONN) "Core curriculum for maternal-newborn nursing" (2000) includes a section on health education, which states that health education should focus primarily on the parents/caregivers acquisition of knowledge and skills about the special needs of an infant exposed to drugs during pregnancy. Teaching should also focus on anticipatory guidance to help parents anticipate and effectively deal with their infant's behaviors. Table 1 outlines key areas of instruction for parents. Important areas of teaching also include self-care, interpretation of infant cues, organization of care to avoid overstimulation, the use of graduated interventions in quieting the irritable baby, and

the importance of providing stimulation to the infant at a level appropriate for that particular infant (U.S. Department of Health and Human Services, 1993).

One issue for infants with prenatal substance exposure is difficulty in managing change. Discharge home represents a significant change for an infant who may have been cared for in the same environment for several weeks. Foster parents may be encouraged to begin to initiate steps in minimizing the effect of the transition (Table 2). Strategies may be used such as bringing in the feeding system (nipples and bottles) that will be used at home, using infant clothing from home, and having the foster parent visit frequently to get the infant used to their touch and voice. A key piece of information to share with foster parents is that sometimes transition to home can trigger an increase in withdrawal symptoms such as irritability, and that some of the measures used in the hospital such as decreased stimulation may need to be used at home while the infant becomes comfortable with the new environment. As multiple professionals will want to follow up with the infant and family, the foster parent will need to take care in the early days following discharge to structure the daily schedule in a way that doesn't overtire the infant.

***Advocating for support of foster families***

There is no universal policy or practice for preparing adults to care for foster children in the United States (Silver et al., 1999b). Although children in foster care spend more time with foster parents than with any other representatives of the health or child welfare system, foster parents often are the least prepared for, and the least supported in, their responsibilities. Health care professionals within the NICU, as some of the first care providers for the infant and their foster family, are responsible for creating an

environment where the parent-infant relationship can begin and for setting up conditions that support a successful transition to home.

In addition to updated health information about the infant, foster parents have identified the need for respite services, support, good communication, and a clear plan for follow-up as key components in preparing to care for an infant with special needs (Barton, 1998; Dozier, Higley, Albus, & Nutter, 2002; Solisay, McCluskey, & Meck, 1994). Foster parents deal with the continued expectation that they care for foster children with increasing needs, within a system that is slowly increasing licensing expectations, and within a society that is increasingly litigious and policy driven. Children's ministries are feeling the pressure to conform to a number of well-meaning but restrictive and often conflicting recommendations from sources such as birth family advocacy groups, health associations, children's commissions, etc. This is all at the same time as they try to manage budget cutbacks for basic programs and services.

The challenge is to develop services which meet the needs of the primary clients (infants and their foster caregivers), address recent best practice research, meet policy requirements, and are flexible enough to adapt to a range of community situations. Few communities have developed programs related to education and support of foster parents caring for infants with prenatal substance-exposure despite the number of infants requiring specialized foster care (Burry, 1999; Marcellus, 2002; Zukoski, 1999). Nurses within the NICU have a unique knowledge of and experience with caring for infants experiencing withdrawal. This knowledge needs to be shared beyond the hospital with community professionals who often may have limited training in infant health, mental health, or development (Vig & Kaminer, 1999). There are many ways for nurses to effectively advocate for the needs of the infants and their caregivers, including

participating in interdisciplinary teams, developing teaching materials to be used not only in the hospital but also in the community, representing the NICU on community committees, teaching in foster parent education programs, providing in-service education for children's ministries staff, and contributing to interagency practice guidelines. Table 3 identifies some broad strategies for consideration when developing services and supports related to foster care.

## Summary

Researchers are continuing to learn more about the effect of early environments and care giving on infants and young children. At the end of the first year of life, typically developing healthy infants are able to regulate their physiological states, modulate their level of arousal, and develop secure attachments to meaningful adults. Infants in foster care due to prenatal substance exposure are at biological and social risk of not meeting these milestones. The period of infancy is a particularly vulnerable period for children's experience of maltreatment and foster care placement (Wulczyn, Hislop, & Harden, 2002).

Relationships between foster parents and infants often are initiated within the NICU. Support of the foster family as they begin to establish their relationship with the infant and their family will contribute to development of an effective early care-giving environment that promotes the well being of the infant. Neonatal nurses have an important role to play, in both the NICU and the community, in supporting successful transition of the infant from the NICU to the foster home in the community.

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**Table 1-1**

**Key areas of parent and caregiver teaching**

| | |
|---|---|
| **Goal:** Health education should focus primarily on the parents' (or the foster parents') acquisition of knowledge and skills about the special needs of an infant exposed to a substance during pregnancy. | |
| Effective feeding techniques | • Avoidance of overfeeding<br>• Waking for feeds if baby sleepy |
| Effective holding techniques | • Swaddling |
| Effective comforting techniques | • Importance of non-nutritive sucking<br>• Avoidance of overstimulation |
| Administration of medication | |
| Self care for parents | • Taking time out when stressed<br>• Controlling personal stress<br>• Continuing work on recovery; avoiding relapse |
| Safety of infant | • Babysitting is provided by competent adult<br>• Review of Shaken Baby Syndrome<br>• Use of crisis nursery (if available) |
| Recognizing and interpreting the infant's cues | |
| Health of infant | • No smoking near baby |

| | |
|---|---|
| | • Discarding pumped breast milk if illegal drug use in the last 12 hours<br>• Importance of pediatric follow-up<br>• Importance of infant development programs<br>• Knowing when to call the doctor |

Modified from: AWHONN Core Curriculum for Maternal-Newborn Nursing, 2000

**Table 1-2**

**Suggestions for Foster Parents: Bringing Baby Home (Reprinted with permission from "Baby Steps": A teaching guide for caregivers of infants with prenatal substance exposure, B.C. Ministry for Child and Family Development, 2002)**

Bringing the baby home requires careful preparation. The following information may be helpful.

***Taking care of yourself:***

Caring for babies can be very stressful and many caregivers forget to look after themselves. To do a better job in the long run, caregivers need to look after themselves both physically and emotionally and have a good support system in place. To look after yourself, consider the following suggestions:

- Eat nutritious meals and snacks.
- Make time for regular exercise such as walking or gardening and learn relaxation techniques.
- Have a system of support (family, friends, babysitter and neighbors) in place.
- Get regular breaks, even if you feel fine.
- Spend time with your partner and close friends.
- Arrange one-to-one time with your other children.
- Take naps whenever you can.
- Hire a babysitter or relief person (who has had a criminal record check) who is experienced in infant care or is willing to get training from you.
- Keep family members, friends, and babysitters up to date on helpful baby care strategies so they can provide support and relief for you.

- Consider hiring someone or getting a family member to help with the household chores, especially during times when you will be very busy with the baby, e.g. when baby first comes home.
- Don't think that you need to do it all. Ask for help, learn to delegate, or let some things go.

***Getting Your Home Prepared:***

Before the baby is discharged from hospital it is important to get your home prepared.

**Baby Equipment and Supplies**

All baby equipment should meet current safety standards. If you are buying used items from second hand stores and/or garage sales keep the baby's safety in mind. Used items such as car seats, cribs, high chairs, and playpens may not be safe. You will need the following equipment and supplies:

- **A camera** – *for great memories!*
- **Crib/baby bassinet:** Some caregivers prefer to keep the baby close by in a bassinet for the first little while. Babies may feel more secure in a bassinet as opposed to a full size crib.
- **Car seat:** Babies are not discharged from hospital without an approved car seat. Your local health unit will have information.
- **Baby swing:** Some babies enjoy the motion of a baby swing. Look for a baby swing that runs on batteries. Wind up swings can be very noisy and often startle babies. Walkers, Jolly Jumpers, and Exersaucers are not recommended
- **Rocking chair:** A must!
- **Baby stroller:** A large hood on the stroller is preferable.
- **Baby monitor**

- **Snuggly**: is great for holding the baby close to your body
- **Other Items:** Formula and bottle/nipple systems, diapers, mild unscented soap, barrier cream, sheets, receiving blankets, facecloths, blankets, and baby clothes.

**Setting Up the Baby's Primary Sleeping Area:**

- If possible, the baby's room needs to be away from the busy areas of the house, e.g. the kitchen.
- The room should have curtains or blinds and a light dimmer or night-light to control the lighting.
- Use paints colors and wallpapers that are soothing.
- Decorate with removable pictures so you can adjust the environmental stimulation according to the baby's needs.
- Use mobiles and music boxes as tolerated by the baby.
- Keep cats and other pets away from the baby's sleep area.
- **KEEP YOUR HOME SMOKE FREE!**

***Bringing the baby home:***

Before the baby comes home, begin visiting the baby in the hospital as soon as possible. Visiting often and for long periods of time will give you an opportunity to learn the baby's cues and give the baby a chance to get to know you. Ask the hospital staff if you can bring in other family members who will be involved in the care of the baby. By discharge, the baby will know your voice, your smell, and the special way you care for him. Determine how and what the baby will be fed at home. As an alternate caregiver or foster parent your help and support will be needed if a mother is breastfeeding her baby (either at mother's breast or through expressed breast milk by bottle). If the baby will be formula fed, find out which formula will be used and which bottle systems work best.

Bring in items from home such as a swaddling blanket or music that the baby can get used to before going home. Work closely with the hospital staff to learn effective care-giving strategies that you can use at home. Be sure to get the baby's health and medical information on immunizations given, prescriptions needed and follow-up appointments with specialists.

***The Baby's First Few Weeks at Home***

Leaving the hospital to come into a home environment can be a big change for babies who may need a longer time to adjust to new things. Babies placed with alternate caregivers or foster parents may be parting from a mother who has been caring for, and perhaps breastfeeding her baby. The baby may also have had frequent visits from other family members and friends.

***When the baby comes home he/she will:***

- Need to adjust to a new home and new caregivers
- Experience small changes such as different nipples or soothers, different clothing, different levels of noise and light, different care-giving routines, different smells and even the sounds of a different language.
- Experience a busy schedule including appointments with health care professionals
- It may take the baby a week or two to adjust to his new environment. To create a supportive environment for the baby, try the following:
- Spend as much one-on-one time with the baby as possible.
- Get to know the baby's likes and dislikes.

- Delay the use of relief workers or babysitters (other than your partner) until the baby has settled in. Once the baby has had time to adjust to his new home, adjusting to other caregivers will be easier.
- Listen to the baby's cues on how much noise, light, stimulation, and activity he is able to handle.
- Use one or two consistent relief caregivers. It might be a good idea to have the relief caregiver come to your home instead of taking the baby to theirs.

**Table 1-3**

**Suggestions for NICU Health Care Providers**

- Maintain up to date knowledge on conditions frequently seen in the infant foster care population
- Develop an understanding of the complexity of the role of foster parent and incorporate that understanding into plans of care and treatment strategies
- Be aware of and acknowledge the practice philosophies and priorities of other disciplines – they are often different and then there are competing interests to be represented within the plan of care for the child.
- Take into consideration the expertise of the daily caregivers
- Ensure the voice of foster parents is represented within decision-making around care of the infant and guidelines for children-in-care
- Be aware of intersystem hurdles for foster parents and attempt to streamline communication/referral practices etc.
- Develop ways of communicating across agencies that support the care of the children and the efforts of the foster families.
- Facilitate connections to early identification and follow-up services

**PAPER 2**

**Marcellus, L. (2006). Looking at families in nursing research: Strategies for study design. Issues in Comprehensive Pediatric Nursing, 29(4), 225-245**

## PAPER 2

### Looking at families in nursing research: Strategies for study design

Family-focused nursing has been most visible in the fields of pediatric and maternal-child nursing, but with the movement toward considering the family as a key social context for health, all areas of nursing increasingly are incorporating family perspectives into theory, research and practice (Young, 2002). Pediatric nurses have clearly identified the importance of studying children within the context of their families (Broome, Woodring, & O'Connor, 1996). Currently, a family-centered approach has become the goal of nursing practice with clients in all settings (Canadian Nurses Association, 1997; Society of Pediatric Nurses, 2004).

For health professionals, knowledge of the social and behavioral processes of health and illness has often emerged from the study of families (Wertlieb, 2003). As it is possible to study the family through the context of individual members, the sum of its individual members, or the individual and the family together, a major issue faced by the researcher is the choice and use of an appropriate unit of analysis (Astedt-Kurki, Paavilainen, & Lehti, 2001). Family researchers in nursing and in other family-focused disciplines (such as family counseling, family medicine, psychology and sociology) continue to call for attention to the family as the focus of study and as the unit of analysis in nursing research (Bengtson et al., 2005; Munford & Sanders, 2003).

In the past 20 years, family nursing has evolved into a specialty area of nursing practice. Although this has helped assist the advancement of knowledge related to the care of families, it also has resulted in this knowledge being limited to specialty journals and conferences. For example, the majority of references located for this article were published in research, family-focused, or theory journals. Few sources were published in

the clinical and/or pediatric nursing journals that are more accessible to practicing pediatric nurses.

The study of families and the health of families is widely acknowledged as being complex (Kazak, 2002), with family nursing research studies frequently criticized in the past as being underdeveloped (Baumann, 2000; Vaughan-Cole, 1998a; Whall & Loveland-Cherry, 1993). However, the field of family research in general is rapidly becoming more sophisticated, no matter the discipline. Recent family research texts provide many examples of innovative family research methodologies that bring diverse and eclectic theoretical insights to the research process that are better equipped to explore the reality of today's families (Bengston et al., 2005; Munford & Sanders, 2003). The purpose of this article is two-fold. A review of the literature on theoretical development of the concepts of family and family research is presented, with this review used as the context for discussion of the process of developing research studies of the family.

**A Good Starting Point: Defining Family and Family Nursing Research**

**Family**

Gilgun (1992) comments that "defining family and family research is not for the faint of heart" (p.32). Multiple analyses of the concept of family from a nursing perspective are available in the literature (Friedman, 2003; Johnson, 1998; Stuart, 1991; Wright & Leahey, 2005). In addition, many other academic fields, including anthropology, human development, psychology, social work and sociology, provide their own perspectives. In North America, families generally have been conceptualized as the nuclear structure of a married mother and father with their biological children. The increasing diversity of families, rapid changes in societal organization, and

globalization have resulted in a greater awareness of variation in family forms and in definitions of the family (Table 1).

Conceptualization of the family takes many forms, and depends on such factors as individual and family history, functions, relationships, biological ties, legal status, and religious or other social group contexts (Johnson, 1998; Stuart, 1991). To recognize this variation, the Canadian Nurses Association (1997) defined a family as "those persons who are identified by the client as providing familial support, whether or not they are biologically related" (p. 2). Realistically however, society continues to define family from a structural biological perspective. For example, for census purposes, Statistics Canada (2001) currently defines a family as a married or common-law couple or lone parent with at least one child. The U.S. Census Bureau (2004) defines the family structurally as a group of two or more persons related by birth, marriage, or adoption and residing together. Additionally, any family that does not conform to the pattern of the nuclear family still is labeled as "alternative" (Cardwell, 1993). The American Academy of Pediatrics, in their Report of the Task Force on the Family, purposefully chose not to operate from the position of a fixed definition but from a functional perspective (Wertleib, 2003). Questioning the nature of "the family" has been open to lively debate in many disciplines (Munford & Sanders, 2003; Thompson & Walker, 1995).

## Family nursing research

Since the 1970s, nursing researchers have been exploring and debating what makes family nursing research different from research in general (Houck, Kodadek, & Samson, 2005). The term *family nursing research* generally refers to research that focuses on the family unit as a whole (Feetham, 1991), which is distinguished from *family-related*

*nursing research* that focuses on relationships between family members but uses data derived from individuals. Vaughan-Cole (1998a) characterizes family nursing research as falling into primarily two main categories: the investigation of family phenomena and the effect of nursing intervention on some aspect of family health. Robinson (1995) challenges that the distinction between family as unit of care and family as context is artificial; she suggests that the term "family nursing research " has served its purpose and that both the individuals within the family and the family itself need to be considered together with one serving as background for the other.

## Evolution of family theory and methodology

As nurses practicing with a pediatric population, it is helpful to reflect on the theories that have influenced development of pediatric knowledge over time. Ideally, theories provide a framework for practice and research. Because the discipline of nursing is fairly young academically, pediatric nursing has historically relied extensively on early general theories of human development. Most of these early theories were in the fields of sociology and psychology and include some reference to context, such as the effects of early experience (Freud), social influence (Erikson), and adaptation to environment (Piaget) (Connard & Novick, 1996). Within these theories, families are usually presented in one of three ways: as the mediator between family members and the environment, as the context itself, or as the cause of health and/or illness (Gillis, 1991).

### Developmental theory

Pediatric nurses educated in the past generation will be familiar with developmental, or lifespan theories. For individuals, Erickson's theory of psychosocial development is applied in stages across the entire lifespan (Erikson, 1950). For families,

theories such as Duvall's eight-stage family life cycle address families from the point of the early stage of marriage through to old age (1977). Each stage is seen as discrete and predictable. Criticisms of these theories include the assumption of homogeneity (lack of diversity), a middle class Eurocentric bias, and the assumption of stability. These theories and other life cycle approaches imply a universal, sequential cycle to family life when they describe the "normal" evolution of a family (Hartrick, 1995). The notion that there are universal patterns of change within family life does not acknowledge the diversity of lived experience and culture of the majority of families in North America and globally (Allen, 2000; Munford & Sanders, 2003).

**Structural-functional**

Within the structural-functional approach, primary attention is given, obviously, to the structural and functional dimensions of the family (Friedman, 2003). The structural dimensions refer to how the family is organized, how the members of the family relate to each other, and the arrangement of the members of the family. Family structure, or organization, is evaluated by how well the family is able to fulfill its family functions. These functional dimensions are what the family does, and includes outcomes such as socialization, reproductive function, health care function, economic function, and affective function. This approach tends to present a static view of the family and minimizes the importance of growth and change in a family (Friedman, 2003). Structures and functions will also vary depending on family resources and challenges, culture and gender roles.

**Systems theory and research**

Ludvig von Bertalanffy, considered one of the most important theoretical biologists of the first part of the 20th century, first developed his General Systems Theory

in a search for an explanation for how the phenomena of life can spontaneously emerge from forces existing inside an organism (Banathy, 2004). He saw the theory as being applicable to not only biological systems, but also to psychological, social, symbolic and historical systems (Vaughan-Cole, 1998b). In the past 50 years, systems theory in general has drifted from its original philosophical organistic roots toward industrial and technological applications (Banathy, 2004).

In family nursing, systems theory has become a dominant approach to development of theory and clinical practice (Clarke, 1995; Hartrick, 1995; Wright & Leahey, 2005). Although there is no clear agreement on the primary concepts of systems theory, the notions of wholeness, organization, and relationships appear central (Kristjanson, 1992). Kerig and Lindahl (2001) suggest that one of the central beliefs of systems theory is that the family *gestalt* represents something above and beyond the individuals' relationships; Aristotle's statement that "the whole is more than the sum of its parts" has come to represent systems theory.

One popular form of systems theory within family nursing is the ecological theory of development. Bronfenbrenner (1979) proposed that an individual develops within a context or ecology. A series of environmental systems (microsystem, mesosystem, macrosystem and chronosystem) interact with one another and with the individual to influence development. Ecological models emphasize the interconnections of events and the bi-directionality of effects between organism and environment (Connard & Novick, 1996). Human development is viewed as taking place within the context of relationships, and the family is conceptualized as the principle context within which human development occurs (Lackey & Walker, 1998)

**Relational theory and beyond**

Ganong (1995) is concerned that much of family nursing research has decontextualized the family and he encourages nurses to think about the possibilities that may lie beyond a systems metaphor or theory. Addressing this concern, Doane Hartrick and Varcoe's (2005) recent family nursing text demonstrates that theoretical knowledge about families continues to advance. These authors are concerned that many of the theories that currently dominate the understanding of family and family nursing are no longer credible, and they offer a relational model as a way to show how families, nurses, and family nursing "exist and occur in webs of inter-relationality that integrally connect and shape people/families' health and healing" (p. 17). The model that they propose is based on three perspectives, hermeneutic phenomenological, critical theory, and spiritual, and encourages nurses to become relational (taking context into account) practitioners in their work with families. Noble (1998) supports this approach by stating that, in family research, it is the relationships that occur over time and their properties that are the proper object of inquiry.

Emergence of more philosophical approaches to family theory is coinciding with the increased use and acceptance of qualitative research methods. Relational theories of family nursing are particularly amenable to study through qualitative methods. A common thread throughout qualitative research is a focus on the construction of meaning (Gilgun, 1992). Despite the availability of multiple methods that capture the meanings of events and experiences of families, qualitative approaches have in the past been underutilized in the field of family research. Moriarty (1990) suggested that the increased use of qualitative research methods in the field of nursing would result in a greater focus on these approaches in family nursing.

**Connecting theory and method: Conceptualizing a family research study**

There are important theoretical, methodological, and interpretive decisions required of researchers conducting family nursing research. An underlying principle for decision-making is to ensure that all the strategic choices reflect the theoretical premises on which the study is built. Well-constructed family research must be internally consistent and congruence needs to be evident throughout the study design, from the definition of family, the theoretical underpinnings, the data collection and analysis measures through to interpretation within the findings and discussion sections (Clarke, 1995; Feetham, 1991; Gillis, 1991; Kristjanson, 1992; Vaughan-Cole, 1998a). The primary consequence of not integrating all components of the research cycle is development of research that may be theoretically inconsistent and ultimately difficult or inappropriate to apply to practice. Figure 1 outlines one conceptual framework that is useful to guide researchers through development of a family research study. In this section, each component of the framework is discussed in terms of development of a research study that uses the family as the unit of analysis.

**Epistemologies**

An epistemology is defined as a theory of knowledge; the "what" and the "how" of knowing (Bengtson, Acock, Allen, Dilworth-Anderson & Klein, 2005). It frames the way families are defined and approached. Nursing knowledge has historically been structured within a positivist biomedical way of knowing that places value on objective verifiable truth. In the past 30 years, alternative theories of knowledge such as feminism and critical theory have contributed to the awareness that knowledge is not completely objective, but that it is created from the assumptions and values that underlie its generation (McIntyre, 1995).

For example, *feminism* is defined as a movement to end sexism, sexist exploitation, and oppression (hooks, 2000). Feminists have long criticized both the research methods and the theories used in the studies of families. Segal (1995) suggests that the discipline of psychology, with its emphasis on the individual and its search for some universal set of potential attributes to explain the behavior of this individual, has proved rather unreceptive to feminism. Feminists have struggled for years to expose the "androcentricism of existing social scientific thinking" (Segal, 1995, p. 301). Ganong (1995) suggests that family nursing research could greatly benefit if more nursing researchers incorporated a feminist theoretical perspective.

One important criticism from a feminist perspective of using the whole family as a unit of analysis is that the voices of those with less power in the family (generally the mother and children) are obscured by those with more dominant roles in the family (the father)(Thompson & Walker, 1995). A counterpoint to this argument is that typically family researchers have relied on one informant to obtain information about the family. The informant usually has been the mother, resulting in what Safilios-Rothschild (1969) historically identified as "wives' family sociology." Fathers also have been underrepresented as participants. Use of the family as the unit of analysis provides the opportunity to draw more fathers into the study. Qualitative research methods such as interviewing, when conducted in a way that is congruent with philosophies such as feminism, have the ability to specifically address power imbalances, oppressive perspectives, and gender issues.

*Critical social theory* is defined as a school of thought that explores phenomena through examination of the contextual effects of power, knowledge and values (Manias & Street, 2000). Critical social theory provides a way of acknowledging the power

differences that exist between individuals and groups, working toward the goals of empowerment, enlightenment, emancipation, and social transformation (Browne, 2000). Similar to feminism, critical social theory provides a counter lens from with which to view family research.

An issue related to creation of knowledge is the historical lack of consideration of cultural diversity within theories, methods, and analyses (McAdoo, Martinez, & Hughes, 2005; Whall & Loveland-Cherry, 1993). For example, Froman and Schmitt (2003) suggest that it is not enough to merely translate instruments into other languages or make cultural adaptations to items on scales, but that consideration of underlying concepts and constructs across cultures is needed. When using theories for research or practice it is important to consider that the most popular early family theories have most often been developed by white, North American/European, middle-to-upper class males within the fields of traditional psychology and sociology, and therefore reflect their assumptions and values. Additionally, theory development also has been influenced by state politics or ideologies such as socialism and communism, with the resultant view of the place of traditional families within these ideologies (Cseh-Szombathy & Somlai, 1996; Zvinkliene, 1996).

**Theoretical concepts**

Theories are classified by their levels of abstraction along a continuum, from the abstraction of grand theories to the precision of clinical theories. Because of the broad scope of grand (or universal) theories, they tend to be difficult to operationalize. The focus of most nursing theories on the individual has also historically limited their applicability to families (Broome, 1998). However, some researchers and clinicians have

searched for evidence of families within these universal theories to make them more applicable to family practice.

There are also a number of intermediate clinical theories or models that have been developed to guide nursing practice. Some examples of these more specific models include the Calgary Family Assessment Model (Wright & Leahy, 2005), the Family Adaptation Model (Drummond et al., 2002), and the Parenting and Childhood Chronicity Model (Ray, 2002). Grey (1998) conducted an integrated review of assessment models used to guide health promotion research for children and their families and identified 13 main groups of models, including medical or physiologic, developmental, community-oriented primary care, stress-adaptation, family systems, and family health promotion.

It is important for researchers to ensure that the phenomena of interest that are chosen for study reflect the overarching theoretical framework or model and the conceptualization of family this is used within the study. Carrying through a consistent epistemology also guides the choice and description of theoretical concepts. For example, a critical social underpinning to the study will most likely influence identification of concepts that address power distribution within members of the family and how their socio-economic environment affects the family.

**Research methods**

No one method is correct for constructing family nursing research (Artinian, 1998). The issue is not which method is best, but which method best answers the research question from the perspectives of the families under study and the researcher (Houck, Kodadek, & Samson, 2005; Kristjanson, 1992). Fisher et al. (1985) suggest that no method of assessment, data management, or design should be excluded from

consideration as long as they are logically consistent with the underlying theory and the constructs being assessed. However, a major weakness in many family studies is choosing methods and tools that were developed for individuals and using them for a family (White & Teachman, 2005). Because family members are most likely at different stages of development, it may also be inappropriate to use a single instrument for all members (Kazak, 2002; Uphold & Strickland, 1989). Research methods and subsequent data collection strategies will need to consider the diversity among family members and, either quantitatively or qualitatively, represent both the voices of the individuals within the family and the perspective of the family.

Several compendia of instruments have been developed that measure family phenomena are available (Draper & Marcos, 1990; Kerig & Lindahl, 2001; McCubbin, Thompson & McCubbin, 1996; Sawin, 1995; Touliatos, Perlmutter & Straus, 2001). However, most of the instruments are quantitative, were originally designed to yield individual data, and do not adequately measure the family as a whole (Sullivan & Fawcett, 1991). Additionally, many of the instruments were developed 10 to 30 years ago and may run the risk of not adequately reflecting contemporary cultural and population diversity (Moriarty, 1990; Van Widenfelt, Treffers, De Beurs, Siebelink, & Koudijs, 2005). When choosing instruments, it is important to consider the underlying assumptions that guided development of the instrument and the fit of those assumptions with the epistemology and theoretical underpinnings.

**Sampling process and ethical considerations**

The process of sampling is more complex in family research (Chandros Hull, Glanz, Steffen & Wilfond, 2004; Moriarty1990). Issues of both logistical and ethical significance have in the past often received little attention, despite the fact that sampling

bias can have a negative effect on the quality of the study and the soundness of the results.

Logistically, recruitment and retention require broader consideration with families than with individuals. Any sampling decisions, for example related to inclusion or exclusion, and the rationale for making them, should be described in the research report (Moriarty, 1990; Uphold & Strickland, 1989). Inclusion or exclusion decisions involve consideration of who will or will not be considered part of the family for research purposes. In determining family membership for recruitment, the researcher needs to refer to the definition of family that is being used for the study to ensure congruence. The researcher will also need to make decisions around the use of strategies to recruit multiple family members that minimize the risk of coercion from either the researcher or other family members. The recruitment process also may be affected by factors such as family size and composition, dynamics, and attitudes about research and the condition under study (Chandros Hull, Glanz, Steffen & Wilfond, 2004).

Ethically, the use of families as the unit of analysis introduces consideration of the vulnerability of individual members, particularly those such as the elderly, the dependent, or children (Margolin et al., 2005). Meaux and Bell (2001) suggest that consideration of family factors such as parent-child relationships, parent-parent relationships, and family power dynamics is necessary to maintain an ethical balance between recruitment and subject protection. If the family composition involves children under the age of consent, the researcher will need to consider issues of assent. The assent process differs from the consent process and, in even though it is not legally mandated, it provides children with an opportunity to express their interest in participating in the study (Lindeke, Hauck, & Tanner, 2000). The assent process is guided by the use of

developmentally appropriate language and methods (Broome, 1999). Inclusion of family members with diminished capacity for decision-making also requires special consideration related to consent.

Meaux and Bell (2001) recommend the inclusion of multiple safeguards to assure protection of vulnerable individuals, at the levels of the institution, the family, and the child or vulnerable family member. A process also needs to be in place to allow for ongoing consent/assent throughout the study and to facilitate withdrawal from the study if a family member is no longer comfortable with participation. National ethics guidelines for research involving humans such as the Tri-Council Policy Statement (Medical Research Council of Canada, 2003) in Canada and the National Institutes of Health Regulations and Ethical Guidelines (2001) in the United States include recommendations to address the issue of inclusion in research and research involving those who are unable to consent for themselves. The Society of Pediatric Nurses (2003) has also released a position statement on the role of the staff nurse in protecting children and families involved in research. This statement includes elements of informed permission, recommendations for obtaining assent, and practice recommendations for staff nurses.

A final challenge is related to retention, which ensures that all family members are involved and have equal opportunity to participate throughout the duration of the study. In addition to maintaining the integrity of the sample, attention to continued inclusion serves to increase the content, depth and quality of data obtained during interviews or observations. As a related caution, family interview methods may not be appropriate for the study of sensitive topics. This again relates back to ensuring the method is congruent with the research question.

**Data analysis**

Data management and analysis also need to fit with the underlying framework. For example, family systems theory is not adequately measured with techniques that test simple linear relationships (Vaughan-Cole, 1998a). Use of systems theory as a framework makes selection of appropriate statistical tools difficult (Krisjanson, 1992; Vaughan-Cole, 1998a), with available statistical tools often violating the basic assumptions of wholeness, circularity and equifinity that are essential to systems theory (Vaughan-Cole, 1998a).

A current direction is development of techniques that can support the analysis of multiple transacting variables over time and the non-linear and layered complexity of systems data (Sayer & Klute, 2005; Teachman & Crowder, 2002). Because many research questions that are of interest to family researchers are multilevel in nature, multilevel analysis techniques such as hierarchical linear modeling are attractive; however White and Teachman (2005) caution that detailed multilevel theory should be developed to support the use of these more complex data use models.

Qualitative methods are particularly suited to collection and analysis of family data because they specifically seek out and accommodate the multiple realities of family phenomena. They have the ability to focus on the processes by which families create, sustain, and discuss their own family realities (Gilgun, 1992). The versatility of qualitative research is also a good match for examining the diversity of family forms, experiences, and the meanings that families make out of those experiences. Additionally, qualitative methods are useful for revealing properties and processes related to family as a unit (Kristjanson, 1992). These properties and processes have the potential to contribute to development of family-level theory and measurement instruments.

These fundamentally different types of data require different types of conceptual handling and discussion (Ransom et al., 1990). From a quantitative perspective, data analysis requires complex decision-making around which statistical techniques to use, which variables to analyze, and how the results should be interpreted (Clarke, 1995). There are many important issues associated with analyzing family level data that is transactional in nature, including when and how to combine individual level data into family level data. Quantitatively, the decision to create group scores from individual data should be based on decision guidelines that acknowledge the benefits and drawbacks of the decisions and an understanding of the data distribution patterns between and among family members (Feetham, 1991). Table 2 outlines some data analysis methods frequently used to aggregate and analyze family data.

Qualitatively, the family research literature provides guidance for the analysis of family data. Data analysis and management strategies need to both preserve a focus on the family and address the interplay between family members (Knafl & Ayres, 1996). The constant comparison method (used in grounded theory) is a useful way of interpreting data from individual family members and the whole family within their own context (Astedt-Kurki, Paavilainen, & Lehti, 2001). Bell, Paul, St-Cyr-Tribble and Goulet (2000) suggest that recursive models of data analysis are suited to the study of family processes, meanings, and interactions. A recursive model is one where analysis repeats back and forth between description and inference, similar to the constant comparative method. Another major challenge in analysis is management of the large amounts of data generated from a family study. Knafl and Ayres (1996) describe strategies such as family case summaries and computer-generated matrices as useful

techniques to reduce large volumes of data while still preserving the family focus of the research.

**Results linkage and dissemination**

Throughout the family research literature, there is a frequent focus on the data analysis stage of a family study. However, there are few sources that refer to the need and strategies for conducting a discussion that addresses results from the perspective of family theory. An example of this shortcoming is found in a study conducted by Lavee and Dollahite (1991) where their review of research papers published in the *Journal of Marriage and the Family* found that only one quarter of the studies included theory in both the study relevance and implications sections. A follow up study by Taylor and Bagdi (2005) found that ten years later, still only one-third of the studies included explicit theoretical content. Researchers also run the risk of conducting a study using the family as the unit of analysis and then only presenting findings from the perspectives of individuals within the families.

Hayes (1997) writes that few studies "complete the circle" back to theory and forward to practice application. A return to the underlying epistemology and theory assists in guiding interpretation of the results and the discussion. It also helps in taking the discussion forward from simply a theoretical reflection to one that considers how the results effect nursing practice. Ganong (1995) suggests that even basic considerations of the definition of the family will help family researchers in designing their studies and in appropriately stating their conclusions.

A final pragmatic suggestion in regard to linking results with the other components of the research conceptualization process is to encourage researchers to report not only their results, but also specific theoretical and practical issues related to

conduction of a family study. Identification of issues, concerns, and innovative strategies will contribute to further refinement of family research strategies. Nurses conducting research should also consider the potential of electronic resources. Typically, there is little room in published research studies to report on methodological issues. One suggestion would be for researchers to make this additional information accessible through the Internet or by email.

**Summary**

Health care providers and researchers are becoming increasingly aware of the influence of family factors on health, particularly chronic diseases (Weihs, Fisher, & Baird, 2002; Wright & Bell, 2004). The social context with the most immediate effects on disease management and with the greatest implications for intervention is the family. Despite these facts, nursing researchers appear reluctant to conduct family studies. Family studies based on individual frameworks are important, but the field of family care also requires integrated studies that contribute to the "particular perspective" of family nursing (Hayes, 1993). Contemporary family health care issues (such as poverty, teenage pregnancy, abuse) are rarely addressed in the generic family literature (Cody, 2000). Hayes (1993) wonders if researchers are choosing to study safer, less risky, less complex topics.

Many conceptual and methodological problems have been identified and discussed, but not yet solved (Bengtson, Allen, Klein, Dilworth-Anderson, & Acock, 2005). It is important that as advances are made in family theory development and in the sophistication of qualitative and quantitative research methods, that family nurse researchers consider these advances together. Reconsideration of the concept of family will provide new directions for future theory and research development. Family nursing

science can only benefit from the availability of multiple theoretical perspectives and research methods that will provide the researcher with a range of tools from which to select to design a study that best represents the family phenomena of interest. Ganong (1995) suggests that unless more nursing researchers emphasize families in their programs of study, development of the field will remain behind other family research fields including sociology and psychology. Until every practitioner (not just family nursing specialists or nurses in practice areas involving children) incorporates a family perspective into her or his practice, clinical knowledge will continue to remain individualistic in focus.

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**Table 2-1**

**Selected Definitions of the Concept of Family**

| AUTHOR | DEFINITION/CONCEPTION |
|---|---|
| Stereotypical nuclear family | One man (the primary provider), one woman with children in a legal, lifelong sexually exclusive marriage. |
| Family nursing text definition (Whall, 1998) | A self-identified group of two or more individuals whose association is characterized by special terms, who may or may not be related by bloodlines or law, but who function in such a way that they consider themselves to be a family. "A convoy of relationships." |
| Canadian Nurses Association (1997) | Those persons who are identified by the client as providing familial support, whether or not they are biologically related. |
| Johnson (1998) | Represents any intra- or interpersonal relationship in which there is a history of concern and caring and the potential for continued commitment to caring. |
| Wright & Leahy (2000) | The family is who they say they are. |
| Gubrium & Holstein (1990) | A social concept without specific place or tangible substance; focus is on relationship. |
| Weihs, Fisher, & Baird (2002). | A group of intimates with strong emotional bonds and with a history and a future as a group. |
| Hartrick Doane (2003) | Where people have the greatest chance of experiencing deep connection. |

| | |
|---|---|
| Hartrick Doane & Varcoe (2005) | A complex process where economics, emotion, context, and experience are interwoven and multi-layered. A relational experience. |

Figure 2-1

CONNECTING THEORY AND METHOD IN FAMILY RESEARCH

(Adapted with permission from Larsen & Olson, 1990)

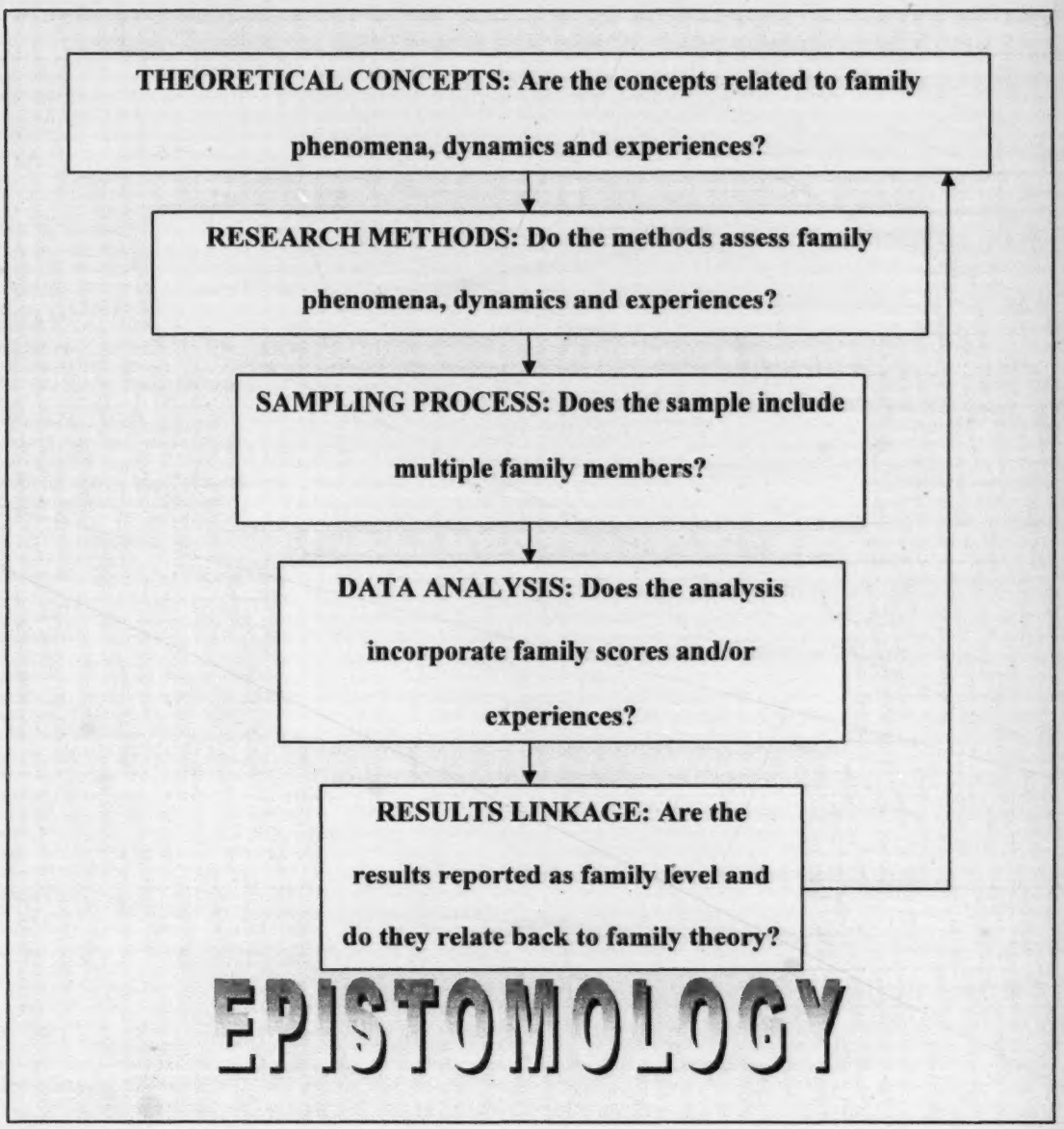
THEORETICAL CONCEPTS: Are the concepts related to family phenomena, dynamics and experiences?
RESEARCH METHODS: Do the methods assess family phenomena, dynamics and experiences?
SAMPLING PROCESS: Does the sample include multiple family members?
DATA ANALYSIS: Does the analysis incorporate family scores and/or experiences?
RESULTS LINKAGE: Are the results reported as family level and do they relate back to family theory?
EPISTOMOLOGY

**Table 2-2**

**Overview of Quantitative Data Analysis Approaches**

| Approach: | Benefits: | Drawbacks: |
|---|---|---|
| Summative | • Assumes that each member of the family has an equal and important role in describing family experiences | • Does not reflect the inherent differences in power and authority that resides in each family<br>• Comparisons cannot be made between families of different sizes<br>• Important information concerning patterns within each family are lost<br>• Problematic when family score exceeds upper limit |
| Family mean | • Upper limit of scale will never be exceeded<br>• Can make comparisons among families with different numbers of members | • Reduces score variance |
| Maximized family score | • Recognizes that events that happen to one | • Risk of inflated measurement error |

| | | |
|---|---|---|
| | member usually have some effect on other members | • Reduced validity of score |
| Difference | • Highlights the incongruity of responses<br>• Contributes to greater knowledge of family dynamics | • Does not reveal direction of difference<br>• Does not reveal the location of the family along a scale continuum<br>• Contains less variance than original scores, reducing the power of subsequent statistical analyses |
| Combined (sum plus difference) | • Easy to calculate, practical | • Assumptions and conceptual underpinnings of both approaches are not congruent, creating problems in interpretation |
| Typological analysis | • Useful in reducing data to a manageable level | • Risk of over-generalizing |
| Multivariate (factor analysis, canonical | • Researcher has the opportunity to insert the level, discrepancy, and | • Requires larger samples<br>• Unable to compare results across studies – no meta- |

| | | |
|---|---|---|
| correlation, multiple regression, discriminate analysis, simple correlation) | order scores into an equation to predict a dependent variable | analysis |
| Cluster analysis | • Able to put family scores together and also preserve individual information | • Requires a large sample<br>• Risk of creation of artificial groups<br>• Complex analysis |
| Confirmatory factor analysis | • Way of discovering the total structure of a data set<br>• Report structural coefficients | • Complexity of statistical approaches<br>• Do not deal well with dependent variable interaction |
| Structural equation modeling | • Allow the probing of interrelationships and also the direction of relationships between variables | • Complexity of statistical procedures<br>• Must be built on theory<br>• Requires a large sample |
| Log linear modeling | • Works well for sequential data<br>• Allows for more complex | • Does not work well with circular or transactional data |

| | | |
|---|---|---|
| | data | |

References: Acock, van Dulmen, Allen, & Piercy (2005), Clarke (1995), Draper & Marcos (1990), Kerig & Lindahl (2001), Sayer & Klute (2005), Teachman & Crowder (2002), Uphold & Strickland (1989).

**PAPER 3**

**Marcellus, L. (2005). Grounded theory methodology and maternal-infant research and practice. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 34(3), 349-357.**

## PAPER 3

## The Grounded Theory Method and Maternal-Infant Research and Practice

Perinatal nursing research has advanced considerably in the past twenty-five years (Moore, 2000). One emerging trend has been the increased use of qualitative methods for conduction of research studies. Nurses have historically been socialized to view the world from a biomedical perspective, but have been finding qualitative methods often more appropriate for answering many of their research questions that have arisen from practice. Perinatal nurses in particular have found qualitative methods helpful in capturing the social, cultural, and relational aspects of their work with women and their families.

Grounded theory is one qualitative method that has been found useful for exploring the interplay between health and social policies and women's health (Wuest, Merritt-Gray, Berman & Ford-Gilboe, 2002). Grounded theorists have been major contributors to a growing body of knowledge about the nature of women's lives and the effect of health and illness experiences on them and their families (Benoliel, 1996). The purpose of this article is to review the grounded theory method and demonstrate the usefulness of the method for research with women and their families. Examples of recent maternal-infant grounded theories will be provided to assist the reader in understanding the research process.

### Looking Back at Qualitative Nursing Research and Development of the Grounded Theory Method

Historically, nursing research, practice and literature has been dominated by the quantitative, or natural science, research tradition. Many currently practicing nurses

were taught that quantitative research was the only way to conduct scientific inquiry (Cox Dzurec, 1989). Over the past 20 years qualitative research has slowly been gaining acceptance as a legitimate form of inquiry. The term 'qualitative research' is general and includes a range of methods and designs (Boyd, 2001). What these methods all have in common is that they approach research questions holistically and with a focus on human experience and the ways in which people create meaning of their lives. Frequently used qualitative methods include grounded theory, phenomenology, ethnography, case study, and historiography. Researchers within nursing and other disciplines continue to explore new and creative methods that have the potential to contribute to our knowledge of human experience. Additionally, components of the grounded theory method, such as constant comparison, are often used within other qualitative methods because of their rigor. Morse and Richards (2002) suggest that the particular niche of grounded theory in qualitative research is that it best identifies and analyzes complex processes.

Benoliel (1996) reviewed the general nursing literature for research reports using the grounded theory method from 1980-1994 and found a large number of studies which focused on processes of adaptation related to women's reproductive health and family development. A hand search review of articles published in the Journal of Obstetric, Gynecologic and Neonatal Nursing from 1998-2002 (a five-year period) found a moderate increase in the number of studies that used qualitative methods, from two in 1998 to eight in 2002. The majority of the studies used an exploratory and descriptive method, and six studies used the grounded theory method.

Grounded theory was developed in the mid 1960's by two sociologists, Barney Glaser and Anselm Strauss, who had been brought together to teach a course on

research in the School of Nursing at the University of California at San Francisco. Their goal was to develop a way of generating theory that stayed close to the meanings and experiences of individuals within the context of their relationships. Their original grounded theory method reflected both Glaser's positivistic methodological approach and Strauss' pragmatist philosophy and symbolic interaction background. Their initial 1967 text, *The Discovery of Grounded Theory,* offered the method as a legitimate way to bring sociology back to field research and encouraged the generation rather than the verification of theory. Glaser and Strauss (1967) felt that the greatest strength of grounded theory was that it goes beyond description and provides a method of developing an explanatory model that accounts for change and variation in human behavior.

**What is Grounded Theory?**

Grounded theory is described in most primary references as an inductive method for qualitative analysis that generates theory from data. The central idea behind the generation of theory is that it is grounded in, and remains connected to, the data (Chenitz & Swanson, 1986; Schreiber & Stern, 2001b). An inductive method is one where the theory emerges from the data, which contrasts with a deductive theory, where the researcher starts with an abstract idea or theory and then tests propositions related to the theory. The central objectives of grounded theory are to identify the trajectory of a basic social process to which people must adapt and to advance development of a theory with respect to that social process (Coffman & Ray, 2002).

Symbolic interactionism is the primary theoretical underpinning for grounded theory. The philosophy was developed as an alternative to traditional conceptualizations of human behavior as simply reactive and behaviorist. From the

perspective of symbolic interactionism, the individual is seen as deriving meaning from shared interaction, action and communication with others in their environment (Blumer, 1954; Mead, 1931). Many of nursing's major theories contain elements of symbolic interactionism. Elements such as development of self, interaction, effect of environmental context, and personal meaning have been found to greatly increase our understanding of human health behaviors and have practical relevance to our daily work of nursing.

Researchers who use grounded theory have found that as a method it is adaptable to many viewpoints. For example, feminists have found grounded theory to be useful because women in particular are enmeshed in social relationships and the researcher is then required to seek understanding of women in their multiple roles (Keddy, Sims & Stern, 1996). Critical social theorists find that grounded theory, through its consideration of environment and context, includes social and political conditions when understanding people's experiences as both individuals and as members of communities. Kushner and Morrow (2003) suggest that as a methodology, grounded theory is flexible enough to accommodate extension of the notion of social processes by other philosophical viewpoints. Recent constructivist advancement of the grounded theory method by sociologist Kathy Charmaz provides researchers with a third approach to conducting grounded theory (Charmaz, 2005).

**Key Components**

Some research studies are misleadingly identified as grounded theories when they are often qualitative descriptive studies. For a study to be consistent with the grounded theory method, it must include several key strategies, including theoretical sampling, theoretical sensitivity, constant comparison, increasingly abstract

consideration of the data, and discovery of a core variable or basic social process which describes the pattern of the phenomenon. Each component is described below and examples are provided from recent maternal-infant research studies that used the grounded theory method.

***Theoretical sampling***

Theoretical sampling is defined by Glaser and Strauss (1967) as "the process of data collection for generating theory whereby the analyst *jointly* collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop the theory as it emerges" (p. 45). This contrasts to traditional quantitative sampling methods that rest on the notions of randomness and vigorous adherence to a sampling plan. In grounded theory, the researcher only plans in advance the initial sampling for data collection; after that, the sampling process is entirely controlled by the emerging theory. Once analysis of the data has begun, hypotheses will emerge from the data that will require the researcher to seek out participants or situations that both confirm and disconfirm the hypotheses, contributing to development of the emerging theory.

For example, in Kearney's (1996) study of mother's stages of recovery from drug use, a diverse sample was intentionally created by recruiting to reflect a range in ethnicity, marital status, socioeconomic status, drug of abuse, and length of time in treatment. When Fagerskiold, Wahlberg and Christina (2000) studied child health nurses and their perceptions of what mothers with infants expected of them, they sampled nurses with varied specialist training and experience in meeting first-time mothers, and also sampled for a range in age and urban versus rural location. An example of sampling to disconfirm a theory is provided by Dobrzykowski and Stern (2003) when

they examined maternal role attainment in first-time mothers over 30 years of age. In addition to choosing a range of participants who were older than 30, they also included a small number of mothers in their 20's for further comparison.

***Theoretical sensitivity***

Theoretical sensitivity is defined as simply being sensitive to thinking about the data in theoretical terms, not descriptive or preconceived terms (Strauss, 1987); it is a way to guard against potential biases that can threaten the rigor of the research. Most researchers begin a study with a certain set of assumptions that they have developed from their experiences and reading. A risk for researchers is then imposing those assumptions onto their interpretations of the data. The challenge for researchers is to attend to all possible explanations for what one is seen in the data, not just to explanations related to preconceptions. Theoretical sensitivity requires the researcher to visualize the theoretical model in the data.

Marsiglio, Hutchinson and Cohan (2000), in their study of the social psychological perspectives of young men about fatherhood, suspected that the participants might respond to the sometimes personal questions with idealized or politically correct responses, so they attempted to conduct the interviews with a non-judgmental attitude and with an emphasis on the value of their feelings and experiences. Kearney (1996) was clear in her introduction that she would be comparing the experiences of recovery for pregnant and parenting women to existing stages of change models from the field of addiction, and indeed found that the women in her study experienced a much more intensive, far-reaching process than what had been described in previous studies of recovery.

Sometimes, concepts that appear relevant at the beginning of the study become less so as the study progresses and a model or theory emerges. Cohen (1999), in her study of transition of the technology-dependent child from hospital to home, initially formed a partial framework of four concepts: technology dependence, transition event, transition process, and the conditional matrix (Strauss & Corbin, 1998). The category that eventually emerged as the core of the theoretical framework with the potential to explain a wide range of behaviors in families was family social status. Initially, the sample was based on criteria related to the technology and geographical location. Once the researcher discovered that there appeared to be some variation in the data based on social marginalization, theoretical sampling based on social status was then conducted.

***Constant comparison***

In traditional quantitative research, analysis does not occur until data collection is complete. In grounded theory the process of analysis begins at the same time as data collection. Constant comparison, the simultaneous collection and analysis of data, is a cornerstone of the grounded theory method. The researcher uses an inductive-deductive approach (going back and forth between the data and the emerging concepts and theory) to generate and extend the theory. This process is not linear, but is circular and involves constantly going back to the data and returning to participants. Benefits of this process include keeping the data and the theory close together, retaining difference in the data, and minimizing the risk of bias from assumptions. The researcher uses data from previous sources to adapt the data collection methods to further the developing theory. For example, a researcher may start out with a guiding question or two, and then based on responses from participants, may choose to focus questions for future participants on certain areas that are appearing to have emerging relevance for the

theory. The researcher uses constant comparison and theoretical sampling together until saturation is reached. Theoretical saturation, also known as theoretical redundancy, is best described as the point when the full range of variation in each category has been portrayed.

In her study of midwives and their facilitation of informed decision-making, Levy (1999) shared extracts from transcription of previous interviews and used them as triggers in follow-up interviews so that the data could develop in greater depth. When Fenwick, Barclay and Schmied (2001) studied the experiences of mothers with infants in the neonatal intensive care nursery, they took their developing concepts back to their participants throughout the study to ensure that their theoretical interpretations were staying close to the experiences of the mothers.

***Raising the level of abstraction: Coding through to conceptualizing***

Structured and unstructured interviews are frequently relied on for data collection. Data collection often follows the pattern of field research (Hutchinson & Wilson, 2001), and researchers are encouraged to use other different data sources, such as documents, observations, videotaping, field notes, media, meetings and informal discussions to add dimension and diversity to the study. The theme "everything is data" has been applied to grounded theory (Wuest, 2000) to reflect the range of sources that are useful in providing information for researchers. Researchers use strategies such as diagramming and development of spreadsheets to organize, guide, and develop the data. Computer software programs are now also available for organization and management of qualitative data.

A final key strategy for raising the level of abstraction is memoing. Memoing is the ongoing process of making notes on the researcher's ideas and questions that occur

during the process of data collection and analysis (Schreiber, 2001). It serves as a record of thoughts about the study, contributes to theory development, and acts as a record of the research process itself (as an audit trail).

Data analysis in the grounded theory method includes the increasingly abstract processes of coding, categorizing, conceptualizing and abstracting. Through these processes, raw data is transformed into theory (Schreiber, 2001). An exciting feature of grounded theory is that the researcher is able to generate their own concepts from the data instead of using or forcing the concepts of others onto the data. The key difference between descriptive studies and grounded theory studies is at this point because the researcher goes beyond categorizing into conceptualizing and abstracting. Some studies that state they use the grounded theory method stall at this point as the researchers under-analyze the data and stay at the descriptive level rather than moving into conceptualization.

Coding is the first step in data analysis and involves preliminary consideration of properties of the theoretical ideas and constructs (Kendall, 1999). There are various ways of conducting coding to assist in organization of the data and maintenance of the connection between the data and the emerging theory. Glaser (1978) describes two levels of coding and Strauss and Corbin (1998) describe three levels of coding. Schreiber (2001) cautions that some of the coding systems may seem complex to novices, so it is important to approach coding as simply aids to theoretical sensitivity, or as a view to understanding the data. No matter which coding system is used, all share the goal of moving beyond description toward development of an explanatory model where not only the main pathway of the experience is described but also how the experience can vary according to individuality and context (Kearney, 2001). A grounded theory that has

the ability to predict change and variation is considered an explanatory theory; the ability to be predictive is useful for direct application to nursing practice. For example,

For grounded theory, conceptualizing is naming an emerging social pattern and trying to capture its imageric meaning (Morse & Richards, 2002), so that what is produced explains the action and its variation. Glaser (1978) suggests asking three key questions: 1) what is this data a study of, 2) what category does this incident indicate, and 3) what is actually happening in the data. References by Glaser and Strauss and others describe coding methods include both levels and dimensions, and vary according to the source; the most frequently used coding techniques include levels of coding (open, theoretical, and constant comparison)(Glaser, 1992), the coding families (Glaser, 1978), and Strauss and Corbin's (1998) paradigm and axial coding.

***Identification of the basic social process***

The theory is considered fully developed when the researcher has constructed an imageric or symbolic representation that explains the relationships among concepts and illuminates the actions and interactions of the participants (Milliken & Schreiber, 2001). The ultimate goal of analyzing qualitative data for process is to account for, or explain, change in the social phenomenon being studied over time. Glaser and Strauss (1967) called this representation a basic social process or a basic social structural process. A basic social process is usually labeled with a "gerund" (an -ing ending) and represents a "theoretical reflection and summarization of the data patterns" (Glaser & Strauss. 1967). A basic social structural process is usually represented by growth or deterioration and is the social structure within the process. Table 1 presents several processes with their descriptions. Glaser (1992) suggested that many researchers do not appreciate the power of abstractedness and the endurance of a compelling concept.

Kearney, Murphy and Rosenbaum (1994) wrote a helpful article with a greater focus on describing the process of identifying a basic social process in their study of mothers who used crack cocaine. They began with coding which initially conceptualized several relationships, including the incompatibility of drug use and mothering, that required women to keep these two worlds apart. The researchers then compared these stories to those of other marginalized populations, such as mothers experiencing poverty, racism and violence. From this work emerged the central process of "defensive compensation", the woman's effort to maintain their mothering standards while using crack. Defensive compensation included defending children from the drug life, shielding one's identity as a mother and trying to make up for the negative effect of crack on mothering.

**Evaluation of the Quality of a Grounded Theory Study**

Nursing, as a practice profession, requires theories that have pragmatic application to their daily work. A good grounded theory provides a template within which nurses can design interventions. For example, Beck (2002) suggested that the four-phase process identified in her study of mothers with twins may be used by clinicians to locate their clients and then apply interventions that have been designed to meet the needs identified in each phase of the process. With grounded theory, the researcher looks not only at the outcome but also the process. This focus on the process is helpful in avoiding a disconnect between description/interpretation and action (similar to the disconnect between theory and practice).

Grounded theory is, by definition and purpose, theory grounded in and tested against human experience (Sandelowski, 1997). MacDonald (2001) suggested that grounded theory itself is inherently verificational – the notion of verification (or

accuracy) is built right into grounded theory, by using strategies such as theoretical sampling and constant comparison as a deductive-inductive approach. Quantitative research is typically evaluated by application of the standards of validity and reliability to maintain the rigor of the study. Morse et al. (2002) argued that these standards remain appropriate for qualitative research and apply not only to the study outcomes but also to the rigor in the research process itself. The Association of Women's Health, Obstetric and Neonatal Nurses has recently formed an evidence-based clinical practice guideline team and created a scoring system to assess the strength of qualitative research evidence (Cesario, Morin, & Santa-Donato, 2002).

Glaser and Strauss' original work (1967) presented the notions of fitness, understanding, generality and control as criteria for judging the quality of grounded theory. These notions have become somewhat modified over the years by Glaser and Strauss themselves and by different researchers, but their original intent remains. Many written reports of grounded theory studies unfortunately do not include any discussion of the accuracy of the study.

Fitness refers to the relationship between the basic social process and the social problem being studied, and also infers that the discovered theory accounts for most of the variation in behavior within the basic social process. The theory needs to fit the area in which it will be used, and ideally has not been forced in its development, but has emerged from the data. Interestingly, the imagery from two separate studies provides us with an example of how theory fits the area in which it will be used. Levy's (1999) process of protective steering, which examined how midwives facilitate informed choices during pregnancy, mirrors Patterson's (1990) process of seeking safe passage for women accessing prenatal care. The continued metaphor of guidance along an uncertain

course reflects the experiences of both pregnant women and the midwives that care for them.

Understanding means that the theory is relevant and makes sense to the people working in the area, enhancing the possibility that it will be useful for practice. This notion was later redefined as "grab", which refers to the ability of the theory to describe "what is going on". Ingram and Hutchinson (2000) feel that their recognition of the double-bind as problematic for HIV-positive prospective women provides useful information for practitioners. Knowing that women feel caught between society's expectations that women should have children and their awareness of the condemnation they receive when pregnant and HIV-positive should assist professionals in being more effective and focused in their practice.

To achieve generality, the theory needs to be not so abstract as to lose touch with the substantive area, but be general enough that it can flex to changing everyday situations. Ingram and Hutchinson (2000) also suggest that their notion of a double bind has application to a range of situations, from mothers with addictions to mothers with teenagers. Dobrzykowski and Stern (2003) take their substantive theory generated from the study of older first time mothers, out of sync, and consider that it may also be generalizable to other lengthy social processes such as fathering, being a mature student, career development, and retirement.

Finally, the theory must enable the person who uses it to have control (or flexibility) over application and adaptation of the theory. Glaser (1999) put it simply and said that good grounded theory "*is what is*, not what should, could, or ought to be" (p. 840). For example, in their study of women's responses to sexual violence by male intimates, Draucker and Stern (2000) enhanced their developing theory by dividing the

women into participant groups according to the types of violence they had experienced. This then allowed examination of demographic factors associated with each type of violence.

**Broadening the Scope of Grounded Theory: Synthesis**

Glaser and Strauss (1967) recommended that once a substantial number of studies are available within a field, researchers should then undertake raising the level of abstraction even higher and create a formal grounded theory. Kearney (1998) noted that currently many qualitative research studies are done in isolation and not as a part of a larger program of research. She suggested that grounded theory research has reached a level of volume and maturity where it is now possible and advisable to bring together topically related studies through the process of synthesis or aggregation. She has demonstrated this process with her own work by using a grounded theory approach to synthesize the findings of 13 qualitative studies into a formal theory of women's experience of domestic violence (Kearney, 2001a). The integrated review approach, using the same grounded theory techniques of constant comparison, coding and searching for a basic social process, seeks to systematically integrate common themes from studies that varied in focus and content (Ganong, 1989). Kearney (2001b) described the benefit of developing formal grounded theory as having a "clinical road map" which will serve to locate our patient's experiences within a phenomenon and its variation. Wuest (2000) has also brought together a number of her previous studies related to women's caring and caregiving and used grounded theory techniques to produce a more substantive theory with greater applicability. This process of synthesis demonstrates the usefulness of grounded theory and its ability to adapt and evolve with the addition of new data.

**Using Grounded Theory in Practice: Relevance for Maternal-Infant Nursing**

Nurses are interested in research and theory that is useful and relevant for them in their daily practice. The idea of a theory that remains grounded in the data, or in the understanding and experiences that people have about a specific phenomena, makes grounded theory appealing. Grounded theory is being increasingly chosen by nurse researchers and graduate nursing students because many of the research questions we have as nurses are about processes or adaptation (R. Schreiber, personal communication, October 7, 2003). The concepts of process and adaptation are highly appropriate within perinatal nursing, as nurses assist families with issues such as adjusting to parenthood, dealing with pregnancy loss, managing the changing body image associated with pregnancy, and learning to care for an infant with special needs.

Fenwick et al's (2001) research of the experiences of mothers who have infants in the neonatal intensive care unit provides a good example of applicability to practice. Their results were striking in that, despite many years of discussion and policy about family-centered care, mothers continued to feel distanced from the care of their infants. This study clearly demonstrates the negative relationship between the two key concepts of the level of control by nurses and the involvement of mothers in the care of their infant. The greater the control by nursing staff, the less involved and more disenfranchised the mothers felt. The variations in behavior by both the nurses and the mothers can be accounted for, or explained by, the theory. Implications from this study include looking beyond policy to the daily interpersonal practices between parents and health care professionals within the neonatal intensive care unit, and renewing commitment from program developers and managers to overcoming barriers to true family-centered care.

Another example of how a grounded theory contributes to practice is Brudenell's (1997) study of women's concurrent experiences of alcohol/drug recovery and transition to parenthood. A core concept of balancing over the first year of parenthood provided guidance for support of the mother. For example, during pregnancy and in the first 4 months after birth, mothering was the focus for the woman. Then, in the 4 to 11 months after birth, the focus shifted back to previous recovery efforts. The first three months were identified by the women as the most difficult. One intervention recommended by Brudenell to address this finding was to teach mothers about developing alternatives to dealing with tiredness and isolation to counteract the risk for relapse in the early postpartum period.

**Summary**

Benoliel (1996) suggested that nurses, in supporting health, need to look beyond narrow lenses such as patient condition or nurse-patient relationship and turn to consideration of meaning within context. Grounded theory provides a way to stay close to the experiences of individuals through their data and through situating meaning and interaction within the larger contexts of family, organization, community, and society. In his 1999 article *The Future of Grounded Theory* Barney Glaser described how in 1967 he suggested to Anselm Strauss that perhaps they were 15 to 20 years ahead of their time. Since then, grounded theory has emerged as an effective way of generating theory that is relevant to both research and practice. By remaining grounded in, and connected to, the data, grounded theory has the ability to be adapted to many contexts, making it useful to the practicing nurse. Sandelowski (1997) called for a returning of value and importance to research that is useful and of substance, research that passes the "so

what" test (p. 131). Knowledge generated from grounded theory has great potential to assist us in our inquiry into the needs of mothers, fathers, infants, and their families.

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**Table 3-1**

**Examples of basic social (psychological) processes and their descriptions**

| BASIC SOCIAL (PSYCHOLOGICAL) PROCESS | DESCRIPTION |
|---|---|
| Out of sync (Dobrzykowski & Stern, 2003) | Women who have delayed their childbearing until after they reach their thirties find themselves out of step with mainstream society and their age-wise cohort. |
| Defensive mothering (Ingram & Hutchinson, 1999) | Mothers with HIV combat a range of threats, including the fear of stigmatization, preparing children for a motherless future, and protecting themselves from negatives fear of illness through thought control. |
| Struggling to mother (Fenwick, Barclay, & Schmied, 2001). | Women with infants in the neonatal intensive care nursery feel disenfranchised in response to inhibitive or controlling nursing interactions; they feel like they are relegated to periphery of care. |
| Protective steering (Levy, 1999) | Midwives facilitating informed choice feel like they "walk a tightrope" as they attempt to strike a balance between |

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| | meeting the wishes of women and also protecting the safety of the woman and her infant. |
| Life on hold: Releasing the pause button (Beck, 2002) | Women mothering twins during the first year of life feel like their life is on hold. "Releasing the pause button" was the process mothers went through as they resumed their own lives. |
| Re-defining myself (Schreiber, 1998) | Women with depression suddenly (cluing in) come to a new understanding of themselves with depression in relation to their world. |
| Enduring love (Kearney, 2001a) | Women in violent relationships reconcile their internal and external conflicts by continually struggling to redefine partner violence as temporary, survivable or reasonable by adhering to values of commitment in the relationship. |
| Seeking safe passage (Patterson, 1990) | Pregnant women accessed prenatal care in a range of ways, but all with the common goal of seeking safe passage through pregnancy and childbirth. |
| Diagnostic confusion (Patterson, 1992) | Women experiencing preterm labor |

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| | experience diagnostic confusion when faced with ambiguous symptoms; they try to make sense of their experience and come to term with knowing a health deviation exists. |
| Constructing compatibility (Hauck & Irurita, 2002) | The maternal process of managing late breastfeeding is characterized as a balance between personal expectations and the often opposite expectations of others. |
| Mazing as coping with fertility (Sandelowski, 1989) | The transition to parenthood of previously infertile couples is described as the process of mazing (negotiating the paths to parenthood). |
| Managing the reemergence of anguish (Rillstone & Hutchinson, 2001) | Mothers found that the mental anguish they experienced following a loss due to fetal anomalies reemerged during subsequent pregnancies. |
| Limiting family vulnerability (Jack, 2003) | Mothers with children at-risk describe their process of engagement with home health visitors as one of limiting family vulnerability through overcoming fear, building trust, and seeking mutuality. |
| Forging ahead in a dangerous world | Women experiencing sexual violence by |

| | |
|---|---|
| (Draucker & Stern, 2000) | male intimates struggle to get on with their lives in a social world they know to be unsafe. |
| Redefining roles (Hall, 1990) | Following the births of their first infants, fathers assumed multiple roles by maintaining their role as wage earner and also by taking on the additional nurturing activities associated with having children. |

**PAPER 4**

**Marcellus, L. (2007). (Ad)ministering love: Providing family foster care to infants with prenatal substance exposure. Submitted to Qualitative Health Research.**

## PAPER 4

### (Ad)ministering love: Providing family foster care to infants with prenatal substance exposure

Infants with prenatal substance exposure, already vulnerable due to substance exposure and other related factors such as family poverty, poor maternal health, inadequate nutrition and prenatal care are often parented within the environment of out-of-home care, or foster care. Infants exposed prenatally to substances tend to enter the child welfare system at a younger age, sometimes directly from the hospital following birth, and require services for a longer period of time due to reasons such as a lengthy maternal addiction recovery process, legal timelines and the requirement for special needs adoptions. In British Columbia (Canada), 14% of children in care are three years or younger, and in the city of Victoria (the capital city of British Columbia) up to 50% of infants coming into foster care have experienced confirmed prenatal substance exposure (Marcellus, 2002).

The child welfare and foster care systems are built on the underlying philosophy that families are the prime mediators and buffers between the child and the community, society and other wider structures (George & Wulczyn, 2003). Much has been written in the literature about issues and policy concerns about the provision of family foster care. However, there does not as yet appear to exist a sufficiently well developed theoretical framework on the nature of being foster families who care for infants at risk. There are few studies available that examine the process by which foster families develop their care-giving skills and take on the role of foster parent to at-risk infants. There is even less research available from the perspective of the foster families; their voices often are hidden behind requirements of confidentiality and the larger systemic issues of child

welfare, and there is little representation of the development of loving connections between infants and their foster families.

The goal of this research study was to identify the process of becoming and providing family foster care giving in the context of caring for infants with prenatal drug and alcohol exposure. Construction of a theoretical framework that explains and accounts for well-functioning family foster homes that care for infants with prenatal substance exposure will serve as a basis for improved practice, policy development, education and training, research and evaluation.

## CONTEXT OF THE STUDY

### *The changing needs of children in foster care*

Foster parents have historically cared for infants and children whose main issue was parental neglect however, the characteristics of infants and children in care have changed dramatically in the past thirty years. A number of studies in the United States have found that for between one-third and two-thirds of children in foster care, parental substance use is a contributing factor to their need for alternative care (U.S. Department of Health and Human Services, 2003). Dicker and Gordon (2004) place this estimate even higher and state that nearly 80% of infants in foster care are prenatally exposed to substance abuse. Supporting the care and nurturing of infants exposed prenatally to alcohol and/or drugs remains a major challenge to social workers, child and youth workers, health professionals and parents (natural, foster, and adoptive) (British Columbia Children's Commission, 1998).

As a specific population of children in care, infants are at risk of development of a constellation of health issues specific to their developmental age. They are more vulnerable to the effects of malnutrition, physical abuse, and emotional deprivation than

any other age group as these all have the potential to impede physical development and brain growth (American Academy of Pediatrics, 2002; AAP, 2000). Clyman, Harden, and Little (2002) suggest that as many as 75% of young children in foster care placement need further developmental evaluation or have a developmental delay. Frequently noted health issues for infants include drug and alcohol exposure, risk of exposure to infectious diseases, failure to thrive, poor weight gain, prematurity, feeding problems, developmental delays, immunization delays, upper respiratory illnesses, and skin conditions.

From an attachment theory perspective, infants placed into foster care are also at risk for later difficulties for multiple reasons – they experience many disruptions in their relationships with primary caregivers, and they have histories of neglect, abuse, parental drug abuse, and/or family instability (Stovall & Dozier, 2000; Wulczyn, Hislop & Harden, 2002). The behavioral and health issues that the infant brings to the interaction often may be considered challenging. Foster parents, professionals, and other caregivers report a range of specific challenges in caring for infants with prenatal substance exposure on a daily basis, including irritability, inconsolability, difficulty with feeding, difficulty settling and being soothed, and sensitivity to change and stimulation.

***The effects of politics, policy shifts and media representation on child welfare and the foster care system***

In North America, foster care services are offered through a range of public, private, and non-profit sectors. In British Columbia foster care services are administered through the guardianship branch of the British Columbia Ministry for Child and Family Development (MCFD). This Ministry in particular has been continually stressed by multiple system reorganizations, frequent changes in senior administrators and

bureaucrats, and dramatic budget cuts. Services for vulnerable children and their families in British Columbia have experienced many shifts in organization and practice priorities in the past fifteen years. These shifts have major implications for professionals working with infants with special needs and their families and caregivers.

An additional and significant influence on policy shifts and politics is the public perception of foster care as shaped by the media. There have been a number of negative incidents in British Columbia involving children in foster care, with high levels of critical and negative media coverage over the years. For example, the severe shaking injury by a foster mother of a baby whose birth mother used methadone during pregnancy resulted in the release of a special report in 1998 by the British Columbia Children's Commission. This report contained a number of major recommendations, including reform of the foster care system, improved treatment and support of infants with prenatal substance exposure, examination of the role of extended family in the care of children, and changes in child abuse investigation practices. The report also resulted in creation of the Safe Babies foster parent education and support program, which was the primary recruiting source for foster families in this study (Marcellus, 2004).

The combination of harsh media coverage, politically related cycles of funding, and constant reorganization has resulted in a challenging context of practice for social workers, foster families, and birth families. There continues to be a focus on the shortcomings of individuals and families, rather than on the economic and social conditions that contribute to poor living conditions for children.

***The shifting demographics of foster caregivers***

Foster care services were conceived in the early 1900s as an alternative to the prevailing use of institutional care for children whose parents were unable or unwilling

to parent in a way that met the standards of the time. Foster care was originally intended to be a only a temporary measure of support for children while their biological families dealt with the social and economic issues that contributed to their parenting difficulties. However, as poverty and other social issues continue to increase in North American society the number of children in foster care and the length of time in which they require services are increasing (Mauro, 1999). Finn (1994) suggests that family foster care is embedded in the larger political economy of the social welfare system, and that rather than being a temporary measure has become a primary child welfare intervention that is based on substitution instead of support.

The British Columbia Ministry of Child and Family Development (2002) defines a foster parent (also identified as a caregiver) as "the person with whom a child is placed by a director and who, by agreement with the director, has assumed responsibility for the child's day-to-day care" (p. 6). British Columbia currently has approximately 10,000 children in care and about 4,000 foster and group homes. Through its Family Care Home Program, the Ministry provides family-based care for children in care (under ministry care, custody or guardianship) as well as supports for foster families. Foster families are conceptualized within this program as providers of "substitute parenting".

Although most foster parent research literature conceptualizes foster parents as temporary caregivers, the status of the infant in the foster family often became that of "pseudoadopted" (Kadushin, 1974). Silver et al (1999) state that the role of foster parents remains ambiguous and is often described as that of either surrogate parents or employees of the child welfare agency. Historically foster parents have been viewed as temporary caregivers or babysitters; children have generally been placed and removed from foster parents' care with little regard to the caregivers' rights or feelings about the

children (Barbell & Freundlich, 2001). However, foster parents are the primary adoption resource for foster children; 59% of the adoptions of children in foster care in 2001 were by the children's former foster parents (U.S. Department of Health and Human Services, 2003).

Child welfare services have traditionally relied on a volunteerism model of foster service delivery. Typical foster families have been those composed of a working father and an at home mother who were interested in giving back to their community. However, across Canada and the U.S. the demand for foster homes is consistently outstripping resources. A number of factors are contributing to this shortage, including a loss of the traditional foster family market due to more women returning to the workforce, reduced recruitment and challenges to retention, children staying for extended periods of time in foster care, the influence of policies related to drug use on child apprehension, increased health and emotional needs of children in care, and decreased supports to families already experiencing poverty and lack of services.

A basic search on the Internet with the key words foster and parent will quickly highlight that many provinces and states across Canada and North America are identifying that they are experiencing a crisis in foster care. A 1991 study done by the National Commission on Family Foster Care in the United States found that as many as 60% of foster parents withdrew from the program within the first 12 months citing lack of agency responsiveness, communication and support as primary reasons for leaving; some U.S. state agencies are reporting losses of 30 to 50% each year (NCSL, 2002). Many children's placements in foster care are longer than the typical foster family career (US HHS, 2003). Similar to other reports on the current state of the foster care system, the 1997 Victoria Capital Region Review of High-Risk Children in Foster Care report found

that foster care resources were stretched beyond their limit, with placement needs far outweighing available services; caregivers reported dealing with issues such as high turnover of social workers, placement of children with increasingly severe health and social issues, increased stress from working with birth families, insufficient relief, poor information flow, and a negative public image (Butler et al.,1997).

Foster parents have also identified that often the care of the child is the simple part and the complex part of their work is the interaction with the child welfare system. Brown and Calder (2000), in their concept map of the needs of foster parents, identified good relationships with social workers and support from social services as two key concept clusters. In addition to support and communication, foster parents have identified the need for education, respite services and a clear plan for follow-up as key components in preparing to care for an infant with special needs (Barton, 1998; Dozier, Higley, Albus, & Nutter, 2002; Solisay, McCluskey, & Meck, 1994). A recent stressor for foster families has been the current emphasis on reunification; foster parents are increasingly being expected to provide support and training for the birth parents of the child in their care. Many of these families have complex social and emotional issues with which foster families do not feel comfortable or qualified to manage.

## METHOD

### *Theoretical approach*

Grounded theory reflects its symbolic interactionist underpinnings in the emphasis on process and meaning, and consideration of perception and meaning within the context of the individual's environment. Grounded theory literature reveals a range of both theoretical and methodological perspectives, particularly between the two founding partners, Barney Glaser and Ansel Strauss, in relation to conduction of

research, methods, and theory development (Glaser & Strauss, 1967) . Grounded theory has been extended and refined in subsequent publications by both authors, in what is seen as divergent directions (MacDonald, 2001). Charmaz (2006) most recently has applied a constructivist perspective to view grounded theories as products of emergent processes that occur through interaction and interpretation, within the worldviews, standpoints, and situations of both the researchers and the participants. Constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of the subject's meanings. A constructivist approach recognizes the symbolic interactionist focus on meaning and the emergent and interactive nature of the grounded theory method.

In grounded theory, the interaction of the researchers and participants profoundly influences the nature of the data. Interpersonal rapport is essential for open and candid sharing of experiences. The use of interview guides and other data collection tools provides only a broad framework for data collection; within this framework the real 'tool' for data collection is the interaction between the researchers and the participants (Munhall, 2001).

***Participants***

Families were recruited through the Guardianship Branch of the British Columbia Ministry for Children and Family Development. I contacted resource supervisors in communities, both urban and rural, and provided them with information about the study. They then identified families that met the initial criteria for sampling and also resource social workers that were interested in participating in the study. The goal of initial sampling was to include family participants who were in at least the

following three time points: foster families who had received initial approval and were waiting for their first placement, foster families who were within their first year of fostering, and foster families with at least three years of fostering experience. The purpose of having sampling at these three points was to have representation of families who had not yet fostered, novice, and experienced families, reflecting the developmental trajectory of becoming a well-functioning foster family care home. Following identification of the initial group of subjects, recruitment decisions were then based on the emerging theory and the principles of theoretical sampling.

In reality, it was challenging to locate families within these three time points. Access to families was limited by the gatekeeper role of the resource worker to recruitment, reluctance on the part of all members of families to participate, and an overall limited number of available families. For example, during the time of data collection no families were recruited that had not yet started fostering.

The final sample consisted of 11 families in five different communities. Because the potential participant pool was small and many of the families had unique characteristics related to family composition, no detail is provided about their demographics, other than to describe that all families included two adult partners and that ten families had their own children participating in the study, with ages ranging from five to 31. At the time of interviewing all but one of the families had at least one foster child in the home. Contrary to the majority of research reports describing foster mothers as having primarily a high school education level, most mothers in this sample had a professional background. Although a significant percentage of foster children are of Aboriginal heritage in British Columbia, no Aboriginal families were interviewed for this study.

Three resource social workers were also interviewed for this study. All the social workers had at least ten years of experience supporting foster families within the government system of guardianship care.

***Ethics review, consent process and confidentiality***

This study was approved through the Health Research Ethics Board at the University of Alberta (Edmonton, Alberta) and through the British Columbia Ministry of Child and Family Development. Because I had previously worked with foster parents and resource social workers in British Columbia, I was clear with participants that this study was independent of MCFD and that their agreeing to or declining to participate would in no way affect their working relationship with MCFD and that no one from MCFD would know if they declined participation. To be included in the study all members of the family currently residing in the home needed to provide consent (adults) or assent (children).

All forms and data collected were kept confidential and when not in use, secured in a locked file or password protected computer file. I transcribed the interviews myself and was the only person who heard the audiotapes. Because the pool of potential participants was small, there was a risk that participants would be recognizable in the data. To minimize this risk, participant names and other identifiers (such as names, places and family characteristics), did not appear on the interview transcription or any other study related documentation, alias names were used in all written material, and the specific geographical locations of the participants within British Columbia has not been specified.

***Data collection and analysis***

The primary strategy of data collection in this study was family interviews. The family was used as the unit of analysis as I felt that family dynamic level data related to relationships and interpersonal skills would best reflect the reality that fostering is a family experience (Kerig & Lindahl, 2001; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Interview questions were open ended and semi structured to encourage subject matter important to the families to emerge. From constructivist and symbolic interactionist perspectives, the interview itself and the meaning within the interview was shaped and co-created by the family and the interviewer.

All family interviews were recorded and transcribed. Each interview lasted between one and two hours. Transcriptions were mailed back to family participants to provide them with the opportunity to edit any information they were not comfortable sharing and to provide further opportunity to elaborate on further thoughts they may have had with reading the transcript. I also made additional recorded and transcribed investigator observation and reaction notes after each interview.

Additional strategies for data collection included follow up telephone calls and emails, attendance at foster parent events and child welfare conferences, examination of relevant government documents related to child-in-care policies and guidelines, and review of professional and lay literature and media. Finally, my standpoint as a researcher in this project was influenced by my previous employment status with the British Columbia Ministry for Child and Family Development (MCFD). For 5 years prior to the initiation of this study I worked with MCFD as the developer and coordinator of the Safe Babies program. During these five years I had many opportunities to learn from foster families and social workers across the province about what it was like to care for

high-risk infants within the child welfare system. I also continue to teach collaboratively with foster parents and social workers in the Safe Babies program in several communities across the province.

Analysis in grounded theory from a constructivist perspective reflected the interpretive process that is applied to the data. Within this approach, coding occurred in two forms, initial and focused. Increased levels of abstraction were reached through comparative analysis that arises from an interactive and open-ended approach to the data (Charmaz, 2006).

***Rigor in the study***

Two measures were taken to ensure that the results of this study met criteria for rigor as defined for qualitative research. First, the emerging analysis was submitted periodically in an interdisciplinary grounded theory seminar group at the University of Victoria (Schreiber, 2002). Seminar discussion provided the opportunity to present the data and analysis to others so that they could critique the plausibility of the emerging theory and call my attention to any biases or incompletely analyzed data. For example, when I brought an early segment of data to the group for analysis, it was pointed out to me that I was using too many leading questions in the interviews; I then adjusted my interviewing style.

The emerging analysis was also discussed with study participants and other foster parents and social workers as a form of member validation. When necessary, categories, properties, and dimensions were modified based on their comments. In this process, persons who are members of the social world under investigation reviewed the findings with me to ensure that they were a legitimate representation of the realities of the participants.

It has been suggested by Morse et al. (2002) that researchers need to focus on processes of verification throughout the study rather than at the end when it is too late. Rigor within this grounded theory study was also enhanced by consistent use throughout the study of strategies such as theoretical sampling and constant comparison.

## FINDINGS

The basic social process that emerged during this study was *(ad)ministering love*. This process represents the tension experienced by families that were committed to providing the love and guidance of a family to an infant with special needs, yet within the restrictions and public gaze of a government child protection system. There are three main phases in this process: preparing to foster, living as a foster family, and ending the fostering role (Figure 4-1).

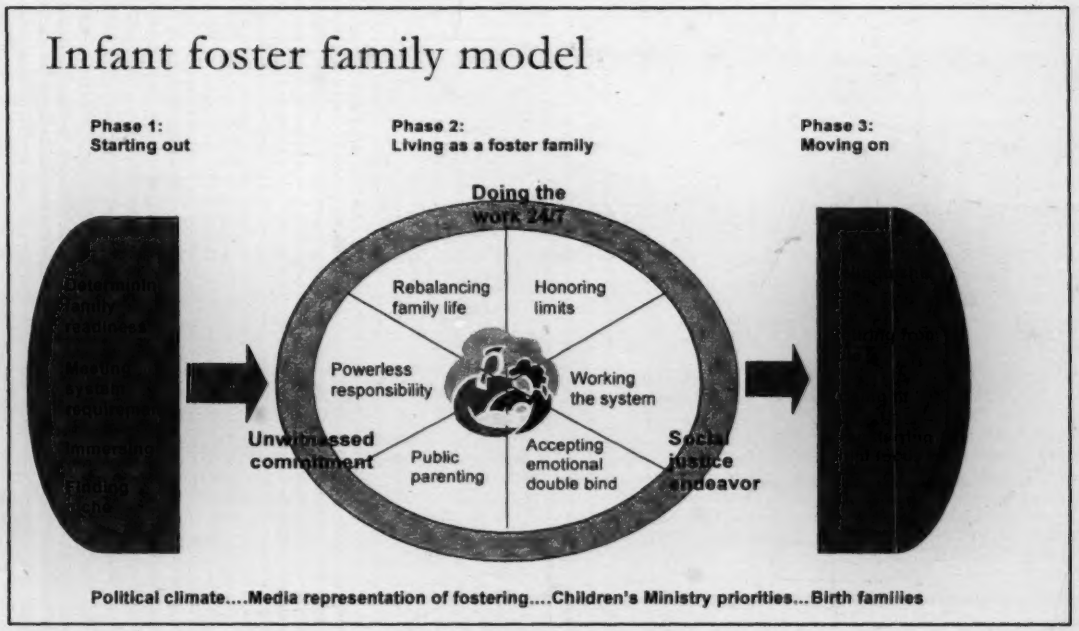


Figure 4-1: (Ad)ministering love: The infant foster family model

## Phase 1: Starting out

### *Determining family readiness to foster*

The familiarity with fostering for many parents started long before their adult life. A number of parents were raised in a family environment where their own parents either fostered or informally provided a safe and consistent place for children in need to visit. Alternatively, some parents grew up in a home that was unsafe or violent and wanted to prevent the next generation of children from experiencing their past personal situation. The most frequent motivation provided by families in this study for being foster parents was the altruistic reason of wanting to make a difference in children's lives. In general, the parents enjoyed looking after children and were interested in sharing their home with other children who needed family care. Table 4-1 presents the range of motivations present within this study group and the literature.

For another group of parents, foster parenting was something they did not know much about and it took a specific trigger to begin the process of considering what fostering actually was and if they would like to foster. Triggers took the form of talking to someone who was fostering, reading an article or hearing about fostering on TV, or recruitment campaigns. Families were also influenced by the situational trigger of being connected to an infant in need of foster care, such as being a birth family member or being connected to someone who knows a specific infant (for example knowing or being a nurse or therapist in the hospital or community).

> *We really had no idea how the whole thing was set up. We had a friend who worked in the ministry and they called and said there's a crisis happening, what do you think? Have you thought about fostering? Would you like to help? And I think we said the next day we were interested and that's how we got everything started.*

For the families who had biological children at the time of starting fostering, attempts were made to ensure that the decision was a family one. However, the ability to make a consensus decision that included children was most likely limited in several ways, primarily due to the age and comprehension of the children, and the challenge in truly knowing what it would be like for the family to foster. One child shared that he *"didn't really care, I didn't know what it was really about. I thought we would see when we got into it."* For most families with younger children, the decision to foster was made primarily by the parents with the best interests of their own children in mind. There was also a perception with some parents that being a foster family would be *"a good learning experience for the children"*, to help them compassionately appreciate the challenges that some families have to deal with. In many family situations the initial desire to foster was

also primarily with the mother, with the father or partner being supportive of the decision.

From a resource social worker perspective, it was important that the underlying motivation and perspective of every member of the family had been taken into consideration. Both foster parents and social workers highlighted how important it was to be realistic about what they were getting into, however they also agreed that until families get into the work (put the theory into practice), there was little opportunity to truly have any idea about what it was going to be like.

> *I always say to prospective foster families, I have two questions. Is fostering for you and your family? And is fostering for you and your family at this stage in your lives? I am a firm believer after all these years of practice that these are two very important questions to ask. That not only is it right, is it right for everybody, and is it right for everybody at this time of your lives? And it might not be, and there's no shame in saying thanks I have got the information, this isn't what I want to do, this isn't what I thought it was going to be.*

**Meeting the requirements of the system**

The administrative process of becoming registered/licensed as a foster family that cares for infants who were vulnerable due to prenatal substance exposure was noted to take two forms. The initial recommended steps include attendance at an orientation session, completion of initial paperwork, completion of a home study, attendance at general foster parent education classes and specialized infant classes, the opportunity to shadow experienced foster families, and the need to establish the initial contract that identified the initial age and gender placement preferences for the family.

Depending on the timing of classes and the number of families requiring home studies, this whole process had the potential to take up to a year to complete.

Another form of becoming licensed that was used particularly when communities were experiencing shortages of foster families, was the abbreviated one; families who were either interested in fostering or had a connection to the infant requiring placement were given the home study and possibly a brief opportunity to link with an experienced foster family, received an infant, and then "caught up" on the other components of orientation that were required by the system.

The home study has been described as onerous and invasive (Grimm & Darwall, 2005), requiring close scrutiny of all aspects of the personal lives of each member of the family. Barb and Sam, foster parents currently caring for their first infant placement, still had the home study experience fresh in their minds:

> *It was horrible. I hated it, not that I hated having to answer the questions, I hated the way the person asked the questions… I really believe that the people who are taking the babies need to answer the questions, they need to be honest, you can't just drop these babies into families you don't know. …It was really intense because it was so rapid, we had to go through so much information in such a short time.*

In 2000 the province of BC developed a standardized 53-hour education program that all foster parents were required to take, even experienced foster parents. Within this program there was one class that focused on Fetal Alcohol Syndrome and Neonatal Abstinence Syndrome. This class provided some very basic information about the caregiving issues for this population on which foster parents needed to develop specific knowledge and skills. There was also a Safe Babies education program that included additional specific information about infants exposed prenatally to alcohol and drugs.

**Immersing for the first time and finding their niche**

Foster families described a range of experiences with their first placement. Although foster care agencies strived to gently introduce families to the role, in reality the shortage of homes frequently led to new families immediately being expected to care for infants and young children with challenging health and behavior issues. This experience was described by foster families as feeling like they were *plunging in* or *in over their heads*. Sam described how their first foster child came into their life.

> *It was a Wednesday, it was 1 o'clock, it was quite funny, because you watch these movies on fostering about how these kids are just dropped off, and then by 1:45 I am sitting here with a baby and I am going, alright! Hi! How are you doing! And you know 45 minutes later you are on your own, and I guess it's well, I will just figure this out now.*

Conversely some families felt like their transition to the role was more natural, particularly those families who had previous experience with child-related day-to-day life, such as caring for infants or children as a day care provider, registered nurse, or being the birth parents or relatives of children with special needs.

Both foster parents and social workers talked about how important it was to know and be realistic about what they were getting into, however, they also acknowledged that no matter how comprehensive the orientation process was, until families got into the work itself (put the theory into practice) there was no real way to appreciate the effect of fostering on their family; one social worker identified this as the *"aha"* moment. Margaret and Basil, an experienced foster mother and father, shared the following advice:

> *Well I think you could probably tell them to take everything they think they know and throw it out the window. Anything you think you know, forget it. You will be starting off*

*with absolutely no knowledge at all. You are not going to be prepared. And it doesn't matter what you think you know. Even if it is someone who has just graduated from some educational program to deal with infants, I don't care, you know nothing. You are going to be hit with things you never imagined and you have to be prepared for it. And things are totally different from one infant to the next. What you think you learned from one you might as well throw out the window again, because the next one could be totally different. And even after all these years they are still hitting me with things I wouldn't have thought possible. So the more you know the more you realize you don't know very much.*

The initial few placements represented a first step to finding out the age and gender preferences for foster children that fit best with the strengths and demands of their particular family. Some of the influences on this process of narrowing the field included the age and needs of the biological children in the family, the work requirements for the parents, the physical space of the home, the activity level of the family, and consideration of parenting strengths for specific age groups. Margaret and Basil described how they came to the place of specializing in infants:

*We find that our skills with the infants are much better. It's not that the issues are not there for them, but it's not so heartbreaking, in some ways. I'm not quite sure how to put it, our hearts still break, but babies don't demonstrate how aware that they are of what's going on and how angry and how frustrated they are. Part of why we like caring for infants is how quickly you see progress, you are able to see the milestones, the results of your efforts put in, you can see them blossom and hopefully you have done some good. With children that are older we're trying to undo, we are trying to rewrite history for them and you can't, you can do the best you can but the history is still there. But with*

*the newborn, I wouldn't say they haven't got any because they have already been affected before they were born but you are starting with a clean slate pretty much and you can imprint good things on it to the best of your ability and that's what we love about it.*

Although the majority of families in this study preferred to care for infants, many times the placements in their home were older. There were a number of reasons for this: a) the child was in infancy at the time of initial placement but stayed in foster care for a prolonged period, b) the infant was part of a sibling group, c) the foster family resided in a smaller community with a smaller pool of foster families, and d) some families chose to keep their scope of practice broader for variety.

**Phase 2: Living as a foster family**

The middle phase of this process is conceptualized as circular and ongoing. Family fostering skills developed continually and experiences were different each time according to the needs and personality of each infant, their birth family, the social workers linked to the case, and the needs of their own family at each particular point in time.

***Rebalancing family life with each placement***

Most of the literature on postpartum family adaptation and integration of a new family member is focused on first time biological parents, and most research on transition to parenthood concludes that it constitutes a period of stressful and sometimes maladaptive change for a high percentage (up to 90%) of new parents (Cowan & Cowan, 1995). Foster families were unique in that they were expected to suddenly care for an infant as a new member of their family with little prior notice and often little background information about even basic things such as bedtime routines, favorite foods, or preferred ways to calm or settle.

*We got a phone call in the morning do you want this baby? We have this baby do you want her? Sure. OK – and within two hours we have this infant in our home and so none of this pre, getting to know the infant, it's like ok this is what you weigh, this is what you drink, she's got a horrible excoriated bottom, this is what you put on it. Just have her.*

Additionally, foster families were expected to let go of this infant with little notice. In some cases this was after a prolonged period of time, sometimes years. In other cases, the stay could be as brief as a few days or weeks.

*Pretty fast turnover, it's like a revolving door sometimes. You're just getting used to a baby and then they are gone and there's another one. We had one little one, she didn't expect any attention, didn't expect any response. She would just make a sound initially and then just comfort herself because she just didn't expect anyone else to come. It was sad, and of course that was a short placement too. You know, before you even got chance to work with her and felt that you could have done something, the placement was over.*

Children's experiences with managing the in-and-out of placements varied with their developmental age. For example, Lisa (age 5) loved to have new babies come to her home because it meant there was someone new for her to play with. Chris (age 12) on the other hand, didn't like putting up with having to protecting his space and property, or not having his mother be as accessible because of the time she needed to devote to supporting an infant that was irritable and difficult to settle. Stressors for foster children in general included sudden changes in their age order position in the family, increased responsibility for household chores, less focused time with one or both of their parents, feeling that their privacy and belongings were being imposed upon, and also not knowing how long their relationship with the infant would last.

The primary observation in regards to the children's response to fostering was that the differences in their perceptions of benefits and concerns were developmentally related. For example, the youngest child interviewed loved to entertain the babies in her home, and danced for them and played with them. The school-aged children that were interviewed demonstrated the egocentric level of cognitive development common to this age by expressing concern that the presence of foster children took from them the valuable time of their parents and privacy within their own home. Adult children shared concern for the health and well being of their parents and wanted to ensure that they weren't overloaded or overstressed.

The family was required to integrate the infant into their daily routines and ways of life. If the infant was experiencing withdrawal from substances or had other health issues, the family needed to adapt their schedules to the needs of the infant. Children needed to learn how to deal with the ebb and flow of the time that their parents had to devote to helping new infants settle into the home and their routine. For example, if both parents attended one of the birth children's sports activities, one parent would have to stay home with the infant. The infant also changed the nature of the home environment.

> *It's sort of annoying when you hear the baby or the child screaming all the time and then we want to just hide downstairs, or go outside. I just like doing things as a family, instead of always thinking about taking the baby along, and taking the bag, or oh we've got to stop and change the baby's diaper.*

Over time, the infants became integrated into their concept of family. Children began to see the infant as a member of their family, as a brother or sister. Other family members and friends identified with family terms – *"like having lots of aunties and uncles"*. This constant rebalancing of family occurred over time and was in conflict with the

developmental cycles of many of the foster families' social supports. They essentially were new families over and over, and in the phase of caring for infants continually. Families who had fostered for many years saw many of their friends move on in lifestyles that were not inclusive of families with small children.

> *We are neither fish nor fowl! With our age, we fit in with the seniors at church, but at home we fit in with the other parents at school. Actually, we had one of the senior gentlemen at church ask, well now that you are retired, why don't you come out to some of the seniors activities? Well, with little children at home I don't feel like a senior! So we're really neither. It's quite difficult that way.*

***Honoring limits***

Limits are defined typically as the furthest boundary beyond which something cannot proceed. Providing foster care became a way for these families to develop insight into the capacity and the limits of their caregiving on multiple levels. On a personal level, each member of the family learned more about themselves as far as their level of energy and patience and what "*pushed their buttons*".

> *We joke that neither one of us have had a night's sleep since the last millennium. But it's not really a joke, it's true. We get very little sleep. But as you get a little older you seem to be able to handle not so much sleep although sometimes I admittedly our butts are dragging but somehow we seem to manage to keep going.*

On a family level, only experience could guide them in knowing whether their family had the time, energy and space to care for one, two or more foster children. This applied to families in different developmental stages, from those with their own young children to those whose birth children were grown and away from home. Bob and

Denise described how, as older foster parents, they found the challenges different from when they were younger.

> *We are probably not as available. And I am tired so I don't have as many family dinners as I would have otherwise. I think we are not as available to our adult kids. I am thankful we didn't do it when our kids were younger. I don't think it would have worked as well. Some also have more children than us, but not us, that would be too much to manage.*

At the systems level, foster families also discovered the capacities and limitations of the guardianship support system as far as the ability to support them, provide respite and plan comprehensively for children entering and leaving their homes. Respite emerged as a key need for many of the families in this study. The BC Ministry of Child and Family Development defines respite care as brief planned stays away from the child's regular foster home (MCFD, 2002). The need for respite varied depending on resources within the immediate family, extended family and friend support, length of time fostering, and respite resources within the local community. The importance of the availability of respite to the well-being of foster families also increased as children aged, particularly for those families caring for children within their home with Fetal Alcohol Spectrum Disorder. Foster families found respite to be the *"light at the end of the tunnel"* as it helped them get through the intense level of care they needed to provide for prolonged periods of time. One set of foster parents did discuss that they felt they were fine without respite and that having their infant go to another home for a few days was too disruptive to a baby that thrived on routine and having the same caregivers available to meet his needs.

> *It is not even worth it to go out sometimes because then you have to deal with all the upset that happens because you weren't home. The kids are too much of a handful for our*

*older children or parents to look after. The lack of relief is a huge issue for us; there is no help in finding people, people who have the skills to look after the kids. I don't even have the energy to find the relief, but I know we need to. It is a huge issue for us at this stage. We are close to burnout.*

All of the adults in the families reported that they each acted as the main source of support and respite for each other. A "*tag team*" approach was common with one partner taking over care to provide the other partner with an opportunity for a break or for some self-care. Because of the challenges of finding skilled respite, families often found that their main source of not just respite, but even social support, was other foster families who could empathize with their needs for rest and also understand the behaviors and needs of their foster children.

> *We have one set of foster parents that we are friendly with and other parents that we are friendly with and that we can bounce things off, and that's pretty much it. They are in our age group and they've got foster children with fetal alcohol syndrome, they're long term placements, and their opportunities to go anywhere are pretty restricted, because their peer group have all raised their children and don't have any more and don't really want children with fetal alcohol syndrome in their house, they don't get invited anywhere ever as a family group as a rule because of that. And so that kind of restricts your social life. So we invite each other back and forth. And that works well for both of us.*

Finally, limits could also not be truly known until families bumped up against or went beyond them. The Brown family had cared for their foster infant for almost a year and was managing well with the routine they had developed. However, when another foster child came to their home, the balance they had created for themselves was upset and all the family members admitted to feeling stressed.

*You know [foster infant] is not a problem because she is right into the routine and she's just like one of our kids and you just go ahead. But when you add another factor, add another little one who doesn't really know what is happening, it makes it more difficult.*

***Experiencing an emotional double bind***

An experience unique to providing foster care was the situation of being expected to care for infants and small children for often prolonged periods of time (years in many cases) but simultaneously being expected to let go and support transitioning the child to their birth or adoptive home within a relatively short period of time. Emotional conflict was inherent within this expectation.

*You get attached, how could you do it and not love them and not get attached. I mean, you can't do it if you don't love them because you don't give them what they need, they need that love, you have to have it in order to survive. When the time comes you have to be able to make that division for yourself. But in the meantime the child doesn't know that, because it's not reflected in your care, but you give the child all the love that you have.*

Although not often presented by the families themselves in terms of grief and loss, continual letting go was identified as one of the most challenging aspects of providing foster care to infants and young children. There were different sub-tones and conditions to every loss that affected the process of letting go and the personal/family reactions to the process. For example, when a child went back to their birth parents, foster families did not necessarily have feelings of confidence about the return depending on the situation of that family. In addition to experiencing loss they also felt worry and concern for the safety and well being of the child. Alternately, if the family had been caring for an infant or young child that had been particularly challenging (or

their birth family was challenging) or was not a good fit for their family, their feelings may be more akin to relief, particularly if the placement was short and relationships had not developed between family members and the infant or child.

Families also reported a gradient effect with their feelings of grief and loss. The intensity of feelings of loss was frequently directly related to factors such as the age of the infant when they first came into the home, whether the foster family took the infant home from the hospital, and whether the birth family was involved. Feelings of attachment appeared to be the strongest for those infants who were placed directly from the hospital into the foster home, stayed for a prolonged period in the home, and had little or no birth family connection. The children in this study also developed relationships with the foster infants in a similar way to the adults in that the younger the infants were when they arrived in the home and the longer they stayed with the family, the more the relationship became like siblings. Because of inclusion of the issue of grief and loss into current foster parent education programs, newer families were able to think about and anticipate the grief they were most likely going to feel when a long-term foster infant leaves their home.

> *Well, I don't think we know what our next step will be yet, because we haven't let one go before that we have had for a long time. So we don't know what we are going to feel. So we are just going to play it slow and see where it goes.*

Loss was also not limited to situations where an infant was moved to their birth or adoptive families. Increasingly foster parents were also being asked to care for infants and children with significant health issues and disabilities that sometimes precipitated an early death. Bob and Sue reported that their emotional experience in response to the death of their foster child with a disability was comparable to the death of a birth child.

The grief and loss experienced by families in this situation is often disenfranchised by society or the system, as their claim to the child is not seen as valid as the claim of birth parents (Schormans, 2004).

One member of the family may also grieve more than another. Knowing the emotional limits of members of the family and the individual ways they all deal with loss, grief, and the rebalancing of family structures is critical to help with dealing with loss. One way of dealing with the pain of continual loss was to reframe the loss as a positive for the family but particularly for the infant.

> *We each go through it differently, the grieving process. I may have worked it through mine already and he is still working through his, and then I am wondering why he is still so grumpy, this is the first few times we went through it you know, but eventually we realized that we each had to go through it, that we had to process it through ourselves, and we couldn't do it for the other person, couldn't hurry the process along. So you have to go through the grieving process… But we have also discovered that in the mathematics of love, love doesn't subtract, it multiplies, right? And you have a chance to make a difference in their lives.*

Also inherent in the emotional relationship that developed between the family and the infant was the notion of perseverance and selfless giving. On the surface families appeared to be sacrificing their time, family space, sleep, ability to be spontaneous, and many other positive qualities of family life to care for infants for what outsiders may not see as sufficient reward. Contrary to public opinion, issues such as contracts and financial compensation rarely surfaced in terms of payback (they did surface frequently in terms of working the system); the rewards had everything to do with relational feedback and seeing infants *"blossom"* in their care.

*We get the love of the children. It's just the love that makes it all worthwhile. It makes everything else just melt away into the background. A highlight is to see the children smile, that's what makes it so worthwhile. The love we have for them and the love they have for us.*

These rewards may also seem small and insignificant to the eye of the outsider, but to families that provided day-by-day care, the smallest steps forward were celebrated as positive milestones for the infants and also as affirmation that the care they were providing was promoting positive development in the infants.

*She has a little routine just before she goes down for her nap where we cuddle together and then she usually lays on my chest and then I lay her down and it's nice. But it's only been in the last little while that that sort of thing has been coming out. You know, you work hard for those rewards.*

***Working the child welfare system***

Most families who entered into fostering did so with the primary motivation of helping children. An unanticipated secondary relationship for foster parents was with the child protection system itself. Families entered into a contractual family care home agreement to meet the requirements of the Child, Family and Community Service Act in British Columbia. Policy documents such as practice guidelines for family care homes, foster family handbook, and standards for foster care regulated the practice of caring for foster families. Until they actually entered into this relationship, foster families had little idea of the scope of influence of the system into the activities of their daily lives. In addition to opening their homes to the presence of child welfare staff, they were also required to accommodate the priorities of related professionals such as public health

nurses, infant development workers, physicians, and family support workers who organized visits with the birth family.

During interviews with all the families "*The Ministry*" occupied a significant position in discussions about the work and challenges of fostering. Although social workers were intended to be supportive, as agents of the state they were often perceived as sources of both help and conflict. Even though families identified that having a good relationship and good communication (and therefore trust) with their social workers was important to their work, opportunities to develop these relationships were limited by overwhelming caseloads and frequent changeover in assignments for social workers. The families that identified they felt listened to by their workers were most often those who had been supported by the same workers for an extended period of time.

***Feeling a powerless responsibility***

Many foster parents described feeling a powerless responsibility; despite having sole responsibility over the day-to-day decisions related to care of the infant, they had no control at all over decisions that affected the long-term future of the infant. Foster parents quickly became aware that within the overall system, they had little voice, a lack of decision-making authority, and a perception that nothing they said would influence what ultimately happened to the infants as far as returning to birth family.

> *What stuck out for me was that, and I'm going to speak primarily about the infant, is that you take on this little one, and you give them the care that you would give one of your own. And on the one hand you are given all of the responsibility to look after this little one and yet on the other hand, it's everybody else's child. Everyone else has a say in what you need to do and it's weird, it's really weird, and I think the other thing is that*

*it's not always consistent. And people within the system have different expectations and to try and find your way through that maze is a little bit challenging sometimes.*

Alternately, some families reported that they felt they were included as important members of the child welfare team. They were included in major decisions, such as assisting with identifying potential adoptive families for the children in their care, participating in team meetings with schools and social workers, and testifying in court for issues related to custody.

*We feel that we are part of the team and and we feel that we are being heard when we speak to them [the social workers] about different things. It also depends on personalities and how we present ourselves. We expect them to treat us as equals. We don't feel that we are inferior because we are parents to the children, we feel like we are doing a very important job…so we think that because we have presented ourselves as professionals, we have been treated that way.*

In addition to a experiencing a steep learning curve in relation to caring for infants with special needs, foster families (primarily the parents) also had a learning curve in relation to the system itself. Similar to Wuest's (2000) theory of negotiating helping systems, foster parents needed to develop the art of navigating the rules of the child welfare system, including issues related to reporting, documentation, confidentiality, surviving allegations, managing short notice placements, tolerating variance among social worker practice, managing contracts, and anticipating changes in the way the system works in response to political and media pressures. Wozniak (2003), in her study of foster parenting in the U.S., characterized families who managed this learning curve and stayed in fostering as "*system survivors*".

***Public parenting***

In addition to living life under the gaze of the state, foster families were also subject to public scrutiny. Depending on the news story of the day, foster families were either valorized for the intensely challenging work they did or condemned for being in it for the money or for abusing vulnerable children in their care. Despite the requirements for confidentiality in sharing information about the infants and children in their care, neighbors and community members around foster families were well aware of the work they did, particularly in smaller rural communities. Foster parents were also aware that the specialized infant care actions they carried out to meet the needs of the infant with prenatal substance exposure (such as reducing external stimulation) were sometimes viewed as inappropriate by casual observers who did not have any knowledge of the infants' health needs and history.

The social workers that supported foster families were well aware of the heightened pressure placed on foster families to have their parenting skills meet a higher level of expertise and effectiveness, despite the underlying philosophy of a family care home model.

> *We need to be constantly reminding our colleagues that foster parents are our next door neighbors, they are people who believe they have something to offer as far as parenting, and are wanting to give back to their commu[illegible]y by caring for kids. They may not come with large resumes about their skills and abilities; they may not come with professional degrees. They are simply people who are prepared to take our kids into their homes and care for them. So I think that sometimes for those who are just content to be that, we forget that there is a standard of expectation, because they have become a public parent.*

Although public in many ways foster caregiving was also overwhelmingly unwitnessed and under validated because the primary location of service was within the privacy of the family home. Although MCFD staff hosted events to acknowledge the importance of the work done by foster families (such as provincial foster parent week, foster parent appreciation events), the validation most appreciated by foster families was by professionals outside the child welfare system such as physicians, nurses and infant development workers who had an understanding of the skills and knowledge needed to do a good job.

> *That's what's meaningful to me. Rather than getting a pot luck lunch from social services or something like that once a year. That doesn't mean anything at all. But having someone say they were happy to release this baby only because it's coming to your home, I mean it's the same as, there's a lot of other foster parents I am sure they feel the same about, but that's what gives you a bit of a boost. Not from anywhere else.*

## Phase 3: Moving on

At some point, every foster family will end their formal contractual agreement with the state. Within this study several families were no longer actively accepting new placements into their home. For some it was because they had long- term placements, for others it was because they ended up adopting the foster children that were placed in their home. Table 4-2 presents a range of reasons present within this study population and the literature.

### *Relinquishing/retiring from the role of foster family*

Although not identified as a specific period of time for recruitment, during data analysis it became apparent that to fully explore the process, sampling was required for families at the end of their fostering careers. Over the study period, only one family was

identified as leaving fostering and it was difficult to access families who had already left the system. Two alternate methods of gaining knowledge of this phase were used. First, at the time of this study a foster parent recruitment and retention project was in process in one region of the province. Within this project exit information was obtained from foster families leaving the system. Second, experienced foster families who had been with the system long term were asked about how long they saw themselves fostering. These families saw themselves providing foster care as long as they were physically and emotionally able. They also were taking into consideration the potential length of stay that current foster children were going to have in their home. For some families, they wanted to commit to the long-term fostering relationship long enough to guide the children into adulthood: *We were hoping to see them grow up. We are trying to take care of ourselves so we can take care of them until they grow up.*

**Losing fit**

The goodness of fit between the infant in care and the foster family caring for them was key to success. Losing fit happened for a number of reasons, including within the family itself and within the family/system relationship. A major change in family composition and role, such as adoption, birth of another child, major family illness, aging, loss of partner, and employment altered the balance that kept the family healthy in the past. Some families experienced changing needs within their own family members that required them to think about leaving fostering temporarily until the balance was better. The Smith family (including several school age children) was very committed to providing family care to the infant in their care, however; only with time did they begin to appreciate the effect of being a foster family on their own relationships and activities. Every member of the family expressed a slightly different perspective of

what they saw themselves doing in the future, including amongst the children themselves.

> *I don't really want to do it for a really long long time, I don't like it. It's just really affects us a lot more, yes. Maybe a couple more years but I don't want to do it till I leave the house (first child). I don't know, like, these kids need our help and there's not too many foster families that really care about these kids, so I don't really know. So I sort of want to stay in there (second child). I want to keep fostering, I want to do it more, but I want to take a break between kids. Like, go with our family somewhere (third child)*

Losing fit also happened between families and the system itself. The data available from the exit surveys reflected the trend for foster families to leave the system due to dissatisfaction or frustration, rather than for developmental factors such as retiring or adopting. The primary reasons cited for leaving fostering were a lack of support, a lack of respect from the system, and lack of respect from the social worker. Half of the respondents indicated that they would not recommend fostering to others; considering that one of the most successful recruitment mechanisms is word of mouth from other foster parents, this lack of support has the potential to translate into poorer recruitment outcomes.

**Transferring child focus**

Foster families who had moved away from full-time active fostering also often continued to retain aspects of fostering and cared for vulnerable children in their communities in other ways. Many families demonstrated Wozniak's (2003) concept of the "*imperative to parent*" by transferring their child focus: they continuing to be connected to caring for children in some way, such as providing respite care,

volunteering with child-related activities, and supporting children of family members or community members who needed assistance.

## DISCUSSION

There is a small but growing body of research and literature on foster family caregivers. Foster parents have traditionally been studied as part of outcomes studies of children in care or as contributing to an intervention for children in care, rather than as the focus of the studies themselves. Many studies rely on foster mothers as their primary participants and some were not fully inclusive of the meaning of fostering to fathers and children within the family who are also greatly affected by the 24/7 in-home nature of fostering.

This study aimed to capture the family meaning of fostering infants with special needs. From a symbolic interactionist perspective, meaning arises out of the social interaction of people, and their interpretation of the experience of these encounters in the environment or context within which they occur (Charon, 2004). Meaning varies between individuals and groups, depending on their construction of experiences. For foster families, there are both individual and collective meanings. For foster families in this study, meaning was further co-created through participation in the research process and through the lens of myself as a researcher.

In this study, fostering emerged as a unique synthesis of care giving and parenting that occurred within the boundaries of a legal contract with the state. Overriding all elements of the process of providing foster care were three threads of experience. These threads were: fostering as a social justice endeavor, doing the work 24/7, and unwitnessed commitment.

### *Fostering as a social justice endeavor*

Many families entering fostering identify the desire to help children as a primary motivator (MacGregor, Rodger, Cummings & Leschied, 2006). Although not explicitly expressed in terms of social justice, many families enter the child welfare system with the broader goal of wanting to contribute to the well being of children in society. Social justice reflects the way that human rights are manifested in the everyday lives of people. Foster families in this study demonstrated a continued commitment to and belief in the power of the family to a child's development. They attempted to give voice to the everyday and immediate experiences of the infants in their care and to advocate for services, supports and circumstances that maximized the infants' future opportunities to grow in health and in a healthy home, whether that be a birth, kin, foster or adoptive home.

Social justice was also embedded in a way that saw families frequently characterizing their work as a ministry, mission, and most of all, a way of being. For most of the participants in this study, fostering was not an add-on role in the family; it became part of their identity. The children in the family, depending on their age, simply saw themselves as helping other children. Many parents shared that they were interested in having their children be exposed to and help children and families who were less fortunate to help them develop as compassionate citizens.

***Doing the work 24/7***

Quality of life for infants and young children is heavily dependent on how they are cared for day to day. A noticeable characteristic of caring for infants is that the reality of the work involves day and night hands on involvement by everyone in the house, although primarily by the parents. There are no breaks for school programs, activities or play dates like there would be for older foster children; caring for infants

requires complete physical and emotional commitment. This was evidenced briefly during the family interviews where even during a one hour interview, the transcription was often blurred by infant crying or babbling, or the flow of discussion required frequent interruptions for feeding, putting babies and other children to bed, answering the phone, and other busy family activities. Interviews rarely lasted longer than 90 minutes because of the multiple demands on family time and the reality of the need to attend to immediate baby and child care. The processes of *taking it day-to-day* and caring for the infant *in the moment* were strategies used by the parents to manage the continuous intensity and the unknown outcomes of the work. 24/7 care frequently resulted in fatigued parents and children, overscheduled families, restricted relational and recreational opportunities for core family members, and a lack of time and opportunity to develop and maintain external relationships.

In addition to the dynamics of caring for infants on a continual basis, the nature and daily rhythms of the foster families were constantly altering (Wozniak, 2003). The processes of negotiating and growing into different family roles and establishing relationships with the infants were overlaid with all the other relationship commitments that came along with the infants, such as the social workers, birth parents, respite support workers, public health nurses, infant development providers and physicians. Medeima (1999) has conceptualized this process as a constant cycle of transforming and reconfiguring; the challenge then becomes maintaining the core sense of family within an environment of perpetual change within the family structure.

***Unwitnessed commitment***

Despite ongoing system scrutiny, the work of fostering infants occurred most often within the confines of home. Like mothering, parenting and family caregiving,

both the demands and rewards of the work remained generally unseen, unknown, and unacknowledged to others. Ray (2002), in her studies of families of children with a chronic illness or disability, notes that professionals, policy stakeholders and the general public are not fully able to understand caregiving and its consequences; making visible the invisible is therefore critical to supporting families effectively.

Similar to family caregiving, there are risks associated with unwitnessed commitment. Exploitation or taken for grantedness of foster family work by societal and social systems is evidenced by factors such as a continued volunteerism approach to fostering, financial under-compensation and insufficient opportunities to provide input into the workings of the system that has such a great influence on the daily life of their family. The ongoing experience of being silenced also runs the risk of contributing to burn out and passivity among one or more family members (Ruddick, 1989).

## IMPLICATIONS FOR PRACTICE AND RESEARCH

Foster care giving has typically been addressed primarily from a practice and research perspective from within the child welfare system and the professional social work field. With the increased health and social complexity of infants and children in care, this is no longer sufficient for best practice. It is not fair to expect the social service field to fully manage the care of this population without significantly greater input and support from the health care system.

### *Practice*

In 2001, the American Academy of Pediatrics (AAP) Task Force on Health Care for Children in Foster Care released its document *Fostering health: Health care for children in foster care*. The purpose for developing this document was to promote the "effective weaving" of health care into the social welfare systems' individual plans for care.

Providing health care for the foster child population is positioned as an *obligation* for health care professionals. The AAP promotes the development of comprehensive health services, including identification of a medical home, preventive health care, developmental screening, mental health services, dental care, and emergency care (AAP, 2001). These services are best offered within a collaborative model of practice with social service programs. Social workers have long been key team members within hospital settings; a reciprocal approach of including health care professionals as team members within child welfare settings holds promise. Innovative strategies include incorporating nurse practitioners or public health nurses within child welfare agencies or developing multidisciplinary health clinics for children within the foster care system (Halfon, Mendonca & Berkowitz, 1995; Kools & Kennedy, 2003).

Although foster parent training for infants with special needs often focuses on skills and knowledge to manage daily care of the infant, it is apparent that training should also substantially include skills and knowledge on supporting core family members during the process of becoming and being foster families, and also information on managing the work associated with the child welfare system itself. Training also should ideally be inclusive of all family members, including the children and other interested extended family members and friends. A "neighborhood" model of training, where foster families bring individuals who will be providing support to the process of orientation and training, may work for some communities (Marcellus, 2006).

***Research***

This study focused on the population of foster families who specialized in caring for infants and infants with prenatal substance exposure. Future research should include studies of foster families who care for children of different ages and stages of

development to see if the core concepts are applicable to a broader group of foster families. It would also build on this knowledge to look at the experiences of different groups of foster family members, including women, men, children and couples. Finally, it would be useful to collaborate with the developing Aboriginal child welfare agencies to hear the experiences of their caregiving families.

This framework also provides a theoretical platform for further testing of the core concepts and for development of interventions that support foster families within one or more of the core concepts. For example, studies may be developed to test interventions such as improved communication between foster families and social workers or a targeted recruitment strategy for respite families and their potential contribution to increased satisfaction and retention of families.

There may also be application of this basic social process to other family parenting and caregiving contexts, including families of children with disabilities or adult caregivers. There are already two strong bodies of knowledge within the grounded theory literature, parenting and caregiving. Many of the basic social processes within these two fields are potentially applicable to the foster family experience, including guarded alliance (Thorne & Robinson, 1989), negotiating helping systems (Wuest, 2001), struggling to mother (Fenwick, Barclay & Schmied, 2001), and protective care (Judson, 2004).

***Limitations of study***

When developing the sampling strategy I considered the benefits and drawbacks of conducting individual interviews with all family members, with solely the foster mothers, or with the family as a unit. For the purposes of this first study of the work of fostering, I chose to start with sampling families as units to develop a broad inclusive

theory that would then provide the basis for a further range of studies that focused on the different roles, relationships and experiences for each of the family members. A drawback to this approach was knowing that family-level discussions would most likely not be as open and frank and that the data generated might be more superficial than that generated within individual interviews.

Despite using a child assent process and reviewing the principle that all family members needed to be in agreement to participate, there was no way to know if children felt coerced in any way by their parents. Additionally, developing rapport with the children of the family was challenging during a one-time interview. However, it was valuable to include children in this study as they provided a unique perspective on fostering that is not often available in the literature.

In addition to the two limitations already discussed (challenges recruiting families and limitations of family interviews), this study was also limited to primarily novice and experienced families as there were no families who had not yet started fostering, and only one family who had left fostering. There were also no Aboriginal families in the sample.

## CONCLUSION

To foster is to nourish, encourage, and help grow (Mirriam-Webster, 2006). Fostering growth in a child requires maintaining positive conditions of growth, including emotional, physical, environmental and system conditions. Dozier and Lindhiem (2006) suggest that what the foster families bring to the relationship in terms of the ability to care for and commit to the child are critical to the child's ability to cope effectively with their challenges (pg. 338).

Foster parenting is frequently characterized as being rife with conflict, paradox, contradiction, intrusiveness, and scrutiny (Miedema, 1998). At the same time, the experiences of foster families include love, achievement, strengthened family bonds, and great satisfaction in watching a child develop. Noddings (2002) defines an ideal home as a place with someone who does the work of attentive love and responds to needs with "a dependable I am here" (pg. 4). Despite significant system, political and public challenges, for vulnerable infants in need of a house and home, foster families are always there. As professionals within the larger health and social systems, our goal is then to figure out how to be "dependably there" for foster families and the infants and children for which they care.

*It's a different life. But it is a chosen life.*

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**Table 4-1: Motivations for fostering**

- Challenging childhood
- Family of origin was foster family
- Stay at home mothers whose children were older but wanted to continue looking after children
- Mothers who had a childcare/daycare background
- Religious or spiritual calling
- Wanting company for biological children
- Feelings of altruism and wanting to give something back to the community

**Table 4-2: Reasons for leaving fostering**

- Lack of agency support
- Poor communication with workers
- Lack of say in foster children's future
- Difficulties with foster children's behavior
- Stress of allegation
- Illness or death of family member
- Increased or changed demands of biological children
- Adoption
- Realized what they were being asked to do was not what they thought it was
- Ran out of steam, burned out

**PAPER 5**

**Marcellus, L. (2007). Supporting resilience in foster families: A model for program design that supports recruitment, retention and satisfaction of foster families who care for infants with prenatal substance exposure. Submitted to Child Welfare.**

## PAPER 5

## Supporting resilience in foster families: A model for program design that supports recruitment, retention and satisfaction of foster families who care for infants with prenatal substance exposure

Foster parents have historically cared for infants and children whose main issue was parental neglect. However, the characteristics of infants and children in care have changed dramatically in the past 20 years. There has been an increase in the number and intensity of health and emotional issues experienced by children in care; many children now entering foster care have been severely traumatized and have special medical, psychological, and social needs that traditional child welfare and foster care services were not designed to address (Rosenfeld et al., 1997; Dicker & Gordon, 2004).

Research has consistently shown that children receiving foster care in general have an increased incidence of chronic medical conditions and a lack of general health care and developmental and mental health monitoring (Committee on Early Childhood, Adoption, and Dependent Care, American Academy of Pediatrics, 2002; Halfon, Mendonca, & Berkowitz, 1995; Kools & Kennedy, 2003). The Child Welfare League of America (1988) coined the term "new morbidities" to reflect the health outcomes that result in children exposed to environmental factors such as poverty, violence, and substance use.

As the health, social and developmental needs of children in care become more complex, foster families are challenged to develop specialized knowledge and skills to effectively address these needs. In addition, the systems of care within which foster families practice have also become more complex. Communities and child welfare agencies across North America are coping with the converging issues of the increased

complexity of the children-in-care population, continued loss of experienced foster families, low levels of retention of new foster families, challenges with recruiting adequate numbers of new families, constant reorganization of child welfare systems, and frequent turnover of child welfare social workers.

This article is based on a grounded theory study of foster families that care for infants with prenatal substance exposure conducted in British Columbia, Canada. A resilience framework is applied to the process for foster families of developing expertise in this field and to describe strategies that have the potential to strengthen recruitment and retention of foster families and to increase the satisfaction of families providing foster care within provincial and state child welfare systems. Through improvement of the well being of foster families, these strategies also ultimately have the potential to optimize health and social outcomes for infants within foster care system.

***The health and social needs of infants in foster family care***

As a specific population of children in care, infants are at risk of development of a broad range of health issues specific to their developmental age. Numerous studies report that children in foster care have a higher incidence than the general population (matched for socioeconomic status) of most physical, mental health, and developmental issues (AAP, 2002; AAP, 2000). They are more vulnerable to the effects of malnutrition, physical abuse, and emotional deprivation than any other age group as these all have the potential to impede physical development and brain growth (Silver et al., 1999a). Clyman, Harden, and Little (2002) suggest that as many as 75% of young children in foster care placement need further developmental evaluation or have a developmental delay. In centers that assess and treat foster children, a primary population is that of the infant or young child who has experienced prenatal substance exposure, and parental

neglect or abandonment often associated with parental drug and/or alcohol use (Woolverton, 2002).

The health needs of children in foster care are strongly shaped by the factors that necessitate foster placement (Halfon, Mendonca, & Berkowitz, 1995). It is acknowledged that children in foster care have already had experiences that have been detrimental to their health and well-being prior to foster care placement (Kools & Kennedy, 2003); many foster children present with poor health profiles at the time of entry into foster care. Frequently noted health issues for infants in foster care include drug and alcohol exposure, risk of exposure to infectious diseases, failure to thrive, poor weight gain, prematurity, feeding problems, developmental delays, immunization delays, upper respiratory illnesses, and skin conditions (AAP, 2001; Silver et al., 1999).

There is also a systemic incompatibility between the experience of frequent foster home placement changes for infants and the need for those infants to develop secure attachments (Morrison, Frank, Holland, & Kates, 1999; Stovall & Dozier, 1998; Wulczyn, Hislop, & Harden, 2002). Bishop et al. (2001) studied a sample of juvenile court records and reported that over half of the infants in their study experienced multiple placements during their time within the child welfare system. A study by Stovall and Dozier (2000) of infants in foster care found that attachment with foster mothers took from 2 weeks to 2 months to stabilize in infants. One clear implication of these studies is that infants in foster care often may not be given sufficient opportunity to develop an enduring relationship with a consistent caregiver.

Substance-exposed infants are often presented as a homogenous group, even though individually they present with a broad spectrum of possible effects, ranging from healthy term newborns with no apparent effects to high-risk births with significant

short term and long term effect (Marcellus & Kerns, 2007; Shankaran et al., 2007). This range in needs requires an approach to infant placement that focuses on "goodness-of-fit". A major challenge within the foster system is to try to match an infant with challenging behaviors to a foster family with the skills and resources to manage their daily care. Infant vulnerability significantly decreases when there is a goodness of fit between parental expectations and the child's characteristics and special needs (Poulsen, 1993).

**Foster families who care for infants with prenatal substance exposure**

Most foster families, particularly those in larger urban centres, specialize in specific age or gender categories. This decision is usually made to match with the ages of birth children within the family, skill sets and interest of the parents. Some families choose to specialize in infants or to further sub-specialize in infants with special needs. One large group of infants with special needs requiring foster care is those who were exposed prenatally to drugs and alcohol during pregnancy. It is estimated that nearly 80% of infants in foster care have been prenatally exposed to substances (Dicker & Gordon, 2001).

Foster families who care for the infant population essentially function as "new families" for prolonged periods of time, including dealing with a chronic lack of sleep and 24 hour a day infant care, managing birth family issues such as daily visiting and breastfeeding, and coordinating infant health care including immunizations, teething, infant development therapy, and nutrition. Because of the age of the infant and their developmental level, foster families also provide the voice of the infant; their familiarity with each infant's cues and behaviors give them the ability to interpret and represent the experiences of the infant.

The British Columbia Federation of Foster Parent Associations (BCFFPA) conducted a joint survey in 2006 with the British Columbia Ministry of Children and Family Development (MCFD) to evaluate the satisfaction of foster parents with the services currently being received in the province. Although not specific to infants this information provides context for the practice of foster parents within the province as a whole. The percentage of responses was very low, ranging from 4 to 9%, with the Vancouver Island Region having the lowest percentage returned (4%). Contributing factors to the low response rate were speculated to include overall poor morale of foster parents, lack of support in regions encouraging foster parents to complete and return the survey, and poor communication at the grass roots level (BCFFPA, 2006). When asked what motivated them to continue fostering, the top reason was their ability to offer love, security, and a sense of family to a child as well as helping children mature, develop and achieve goals. However, their general positive feelings about fostering were being affected by feelings of thanklessness and increased vulnerability, a perceived lack of respect from MCFD staff, increased feelings of isolation, and less financial stability.

**Resilience as a philosophy underlying foster family program development**

Resilience may be simply defined as the maintenance of positive adjustment under challenging life conditions (Health Canada, 1997). Historically, the concept of resilience emerged from the studies of individuals who were dealing with major and often devastating stresses and was considered a personal trait. Thinking has now advanced to consider that resilience is more than simply an isolated individual characteristic or a personality trait; it may be affected by one's experiences, personal genetics, surrounding environment and supports (Atwool, 2006; Kaplan, 1999; Masten, 2001).

In most key theoretical discussions in the literature, resilience is conceptualized as an outcome of the dynamic interaction between two counter forces - protective processes and vulnerability processes. Protective processes (strengths and capacities) develop and act at several levels, such as within individuals, families, communities, and societies. Vulnerability processes (risks or adversities) also develop and act at several levels and can be operationally defined in diverse ways, most commonly as indicators of risk, such as socioeconomic status, life event stressors, health state, or environmental threat. (Drummond & Marcellus, 2003). Interventions with foster families to promote resilience may be designed to focus on both protective and vulnerability processes, at the level of the infant, the caregiver, the interaction, and/or the broader environment in which the interaction takes place.

**Resilience and infants**

Infants and young children will have different vulnerabilities and protective processes at different ages and points in their development. The requirements to support or counter these processes will also most likely change over time and in relation to the environment in which the child is being raised. Rouse (1998) describes characteristics of resilient, or competent, infants as having an easy temperament, being socially responsive, and displaying features of self-regulation such as impulse control and gratification delay. Analysis of longitudinal resilience data finds that infants who were agreeable, friendly, relaxed, responsive, self-confident, and sociable are more likely to be resilient in their adult years (Werner & Smith, 1992).

The caregiving environment particularly affects resilience in the infant population. There has been a recent trend in research that confirms the importance of environmental variables in the long-term outcomes of children. Lester, Boukydis, and

Twomey (2000) have developed multiple risk models for their study of outcomes in substance-exposed infants and children and have incorporated environmental conditions as protective factors. Ann Streissguth (1997), a leading U.S. FASD (Fetal Alcohol Spectrum Disorder) researcher, identifies a consistent caregiving environment in the first six years as one of the key factors in improved outcomes for children with FASD. Environmental factors such as competent caregiving and early relationships are increasingly presented as playing a major role in determining developmental outcomes for infants and children and playing a considerable role in enhancing healthy physical, emotional, and social development of infants (Committee on Early Childhood, Adoption, and Dependent Care, American Academy of Pediatrics, 2000; Heller, Smyke & Boris, 2002; MCFD, 1998). Features of a protective environment for infants include consistent and responsive care within a trusting and loving relationship, by caregivers who are knowledgeable, competent, and supported in their work by communities, systems, and policies.

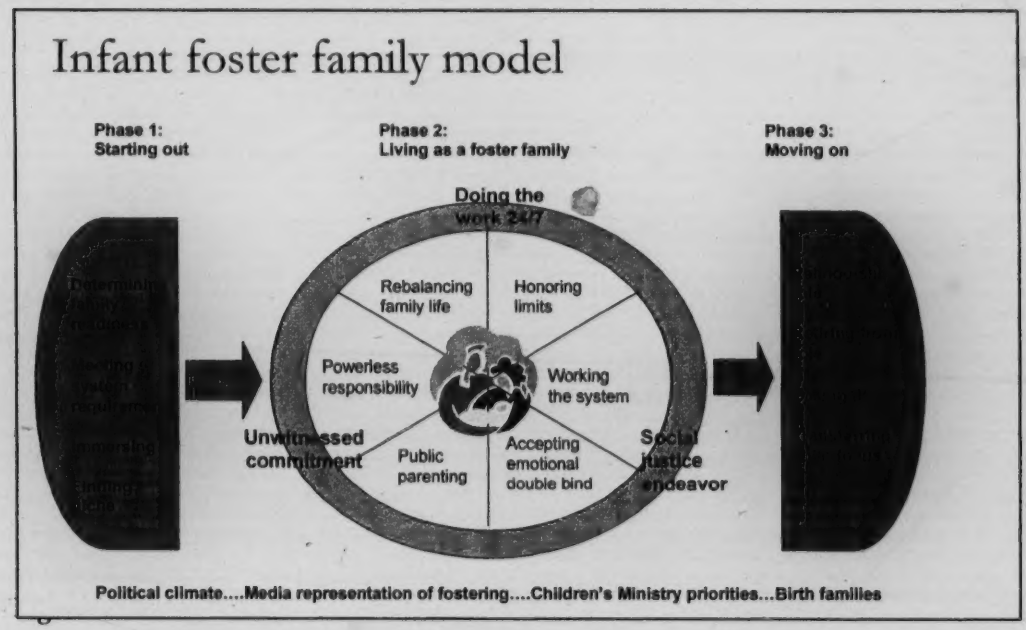
Vulnerability processes for infants with prenatal substance exposure in foster care are numerous. In addition to the potential range of health and developmental issues, from an attachment theory perspective infants placed into foster care are also at risk for later difficulties for multiple reasons – they experience many disruptions in their relationships with primary caregivers, and they have histories of neglect, abuse, parental drug abuse, and/or family instability (Stovall & Dozier, 1998). Additionally, infants with prenatal substance exposure may have spent prolonged periods in a neonatal intensive care unit being cared for by multiple staff members, or they may have entered foster care from the home of the birth parents and may have experienced irregular and inconsistent daily care (Marcellus, 2004). The behaviors and health and social issues that

the infant brings to the interaction often may be considered challenging. Foster parents, professionals, and other caregivers report specific challenges in caring for infants with prenatal substance exposure on a daily basis, including irritability, inconsolability, difficulty with feeding, difficulty settling and being soothed, and sensitivity to change and stimulation.

**(Ad)ministering love: An infant foster family care model**

A 2007 grounded theory study was conducted in British Columbia, Canada with foster families that specialized in caring for infants with prenatal substance exposure. The basic social process (the core experience) that emerged during this study was *(ad)ministering love*. This represented the tension experienced by families that were committed to providing the love and guidance of a family to an infant with special needs, yet within the restrictions and public gaze of a government child protection system. There were three main phases identified in this process: preparing to foster, living as a foster family, and ending the fostering role (Figure 5-1). The next section of this article describes the steps within each of these three phases experienced by foster families.

This model provides a framework for targeted efforts to support foster families at the different stages of their development. Table 5-1 outlines strategies within each phase of the model that addresses steps families take in this process.




Phase 1: Preparing to begin fostering Potential foster families were *triggered to look into fostering* in many ways, including exposure in their own family or social circle, reading about fostering or seeing a commercial. Other parents were internally motivated by reasons such as personal experience with a challenging childhood, a spiritual calling, or an altruistic desire to contribute to a community need. It was important at this point that all members of the family, including children, had the opportunity to contribute to the final decision to proceed with the steps needed to become licensed or approved as a foster family.

Once potential foster families were linked initially into the child welfare recruitment system, there were a number of steps that they needed to complete to *meet the system requirements*, including a home study, orientation and education programs, criminal record checks, and establishment of contracts. These steps, particularly the home study, were time consuming and intrusive for the families. At this time, foster

families were also expected to specify if they had a preference for an age group or gender for placement.

Once approval was received, families experienced *an immersion* into the world of fostering with their first placement. For some families, this went more smoothly than others. For the majority of families it was an eye opener into the scope and depth of the effect of this new role on their family life.

The first few placements provided opportunities for families to *find their niche* as far as the age and gender of foster children that worked with the structures and strengths of their own family. Families that specialized in fostering infants were passionate about providing the intense 24/7 care and love that infants with challenges needed to develop and thrive.

**Phase 2: Living as a foster family**

*Rebalancing family life* was a challenge for families as they managed the ongoing cyclical rhythm of bringing infants and children into their life and letting them go. Family routines, roles and activities and even the environment of the home were all affected by the presence of infants and young children with substance exposure who needed interventions such as routines and decreased stimulation to manage their sensitivities.

This ongoing rebalancing required a commitment on the part of all family members to *honor the limits* of everyone within the family. Knowing when patience levels were reached or when a break was needed was important to keeping the family healthy and positive with energy to keep fostering. It was also acknowledged that there were limits that affected the family's well being on a number of levels, including individual, family, and systems.

A double bind is a situation where a person receives two conflicting or contradictory messages. Foster families caring for infants experienced an *emotional double bind* as they were expected to fully invest emotionally with each infant to provide an environment that promoted attachment, yet they also had to be able to release the infant on short notice to another birth or adoptive family. Although not usually presented within the terms of grief and loss, all family members had to learn how to deal with loving and letting go with each infant.

An unanticipated component of fostering was *learning to work the child welfare system,* including its rules and regulations and its political underpinnings. Foster families have identified that often the most challenging part of the role was not providing care for an infant with special needs, but dealing with the expectations and parameters of a complex government system.

Foster families also consistently reported that their role within the child welfare system was one that was structured as *having a powerless responsibility;* despite having sole responsibility over the day-to-day decisions related to care of the infant, they had little control over decisions that affected the long-term future of the infant.

Foster families conducted their work not only under the scrutiny of the child welfare system but also in the eye of the public. Being a *public parent* came with heightened expectations of parenting skill and family life that were not necessarily supported with resources.

**Phase 3: Ending fostering**

Although some families ended their fostering role from a *retiring* perspective due to aging of one or both parents, in most cases "losing fit" was the reason to end fostering. *Losing fit* happened for a number of reasons, including within the family itself

and within the family/system relationship. A major change in family composition and role, such as adoption, birth of another child, major family illness, aging, loss of partner, and employment changes places altered the balance that kept the family healthy in the past. Increasing dissatisfaction of the family with expectations and restrictions of the system also contributed to an imbalance between the benefits members of the family felt they received from fostering in comparison to the stressors with which they dealt.

Most foster families who discontinued their formal relationship with a child welfare agency did not suddenly end their mission or goal of helping children in need. Rather, they *transferred their child focus* to another form of volunteerism or community support of children. For example, they provided care to children of family or friends, continued to parent their adopted child, or volunteered with programs that cared for vulnerable infants and children.

**Translation of the infant foster care model within a resilience framework**

Application of a resiliency framework to the infant foster care model also provides a useful template for considering the effect of the current child welfare system on the practice of foster families and how adaptations to the work and function of relationships within the system and the system itself may be of benefit in strengthening the support of foster families, potentially resulting in improved retention and satisfaction. Figure 5-2 presents five of the core concepts from the infant foster care model and interprets them from the protective factor and vulnerability factor approach of a resilience framework. Some concepts have implications closer to the family levels, while other concepts come into play at the system and society levels, indicating that an effective program to retain foster families should contain strategies of support at multiple levels.

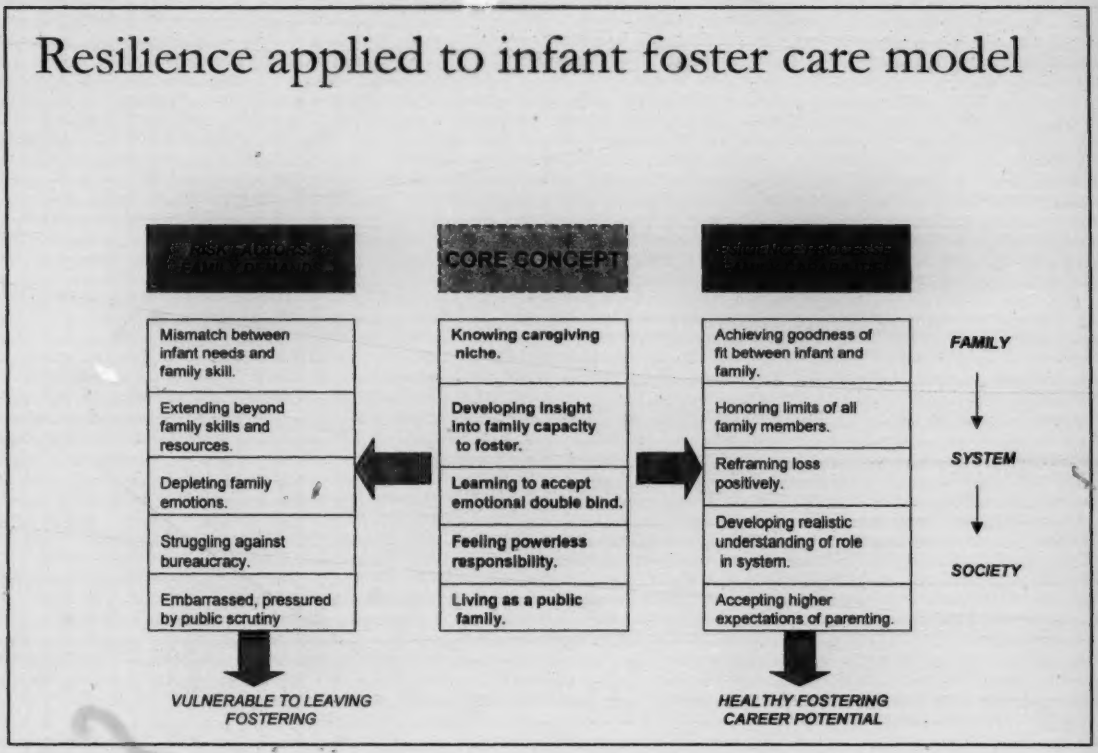

Resilience applied to infant foster care model
CORE CONCEPT
Mismatch between infant needs and family skill.
Extending beyond family skills and resources.
Depleting family emotions.
Struggling against bureaucracy.
Embarrassed, pressured by public scrutiny
Knowing caregiving niche.
Developing insight into family capacity to foster.
Learning to accept emotional double bind.
Feeling powerless responsibility.
Living as a public family.
Achieving goodness of fit between infant and family.
Honoring limits of all family members.
Reframing loss positively.
Developing realistic understanding of role in system.
Accepting higher expectations of parenting.
FAMILY
SYSTEM
SOCIETY
VULNERABLE TO LEAVING FOSTERING
HEALTHY FOSTERING CAREER POTENTIAL

**Figure 5-2: Interpretation of the Infant Foster Care Model from a Resilience Perspective**

### Knowing caregiving niche

All families come with their own strengths and challenges, including skills that fit with particular age and gender characteristics of children. The skill base of families that care for infants is completely different from that for example needed to care for adolescents. Some families are more aware than others of their own skills and strengths. Social workers involved with recruitment, education and resource management play a key role in helping families become aware of what will fit best with the strengths that their family could bring to fostering. Accurately determining this match helps with achieving goodness of fit between infant and family and with sustaining the family's

satisfaction with the work of fostering. Alternatively, a mismatch between infant needs and family skill will not only lead to dissatisfaction of the family with the work they are doing, but also potentially to decreased health and developmental outcomes for infants, as poor attachment is a risk factor for infants who are dependent on the family to meet their physical and emotional needs (Cole, 2006). The relationship needs of infants in care need to be considered just as carefully as safety and health needs to support optimal development

**Honoring limits**

Gaining insight into their capacity to foster requires a commitment on the part of all family members to pay attention to how each member of the family is coping with having foster children in the home. In addition to the age and gender of children, the number of infants and the length of time they stay in the home are also important. A challenge in particular with infant placements is that although they are often presented initially as only needing a short placement period, many end up continuing to stay in the home for months and years.

One risk when considering limits is that the focus is often on the parents; the opinions of children in the family may be overlooked. Birth children have reported feeling marginalized within their own family and feeling bumped out of place due to disruption of age order and gender balance within their family. Heidbuurt (2004) points out that parents share that the bottom line for them with continuing in the foster parent role is the welfare of their biological children. Therefore if the entire family and particularly the biological children are not supported during the experiences of fostering, the foster placement in the short term and family retention in the long term may fail.

**Learning to accept emotional double bind**

Foster families who are able to successfully manage the emotional double bind inherent in fostering work have been able to positively reframe what are essentially multiple experiences of loss. By focusing on the future benefits for a foster child, such as returning to a birth family member or being adopted, families are able to manage their feelings of sadness and loss and continue with the work of once again reinvesting their emotions in another child.

Families who experience successive losses without adequate reflection or support during grief and recovery may find themselves emotionally depleted and unable to commit themselves sufficiently to the next infant or child placed in their home (Dozier, 2001; Sumner-Mayer, 2003). They may also find themselves struggling to find the inner resources to deal with issues within their own family life.

**Feeling powerless responsibility**

A lack of clarity about roles and responsibilities is consistently cited as a key reason for foster families leaving the system (Gibbs, 2005; Rhodes, Orme, & Buehler, 2001). In particular, foster parents keenly feel the divide between the input they felt they should have into decision making and the lack of input they feel they have as part of the child welfare team. The experiences of infants are observed and translated by their daily caregivers; foster families are able to bring the voice of infants to the table. Foster families often feel like they are the only support available for the infants and children in their care and translated their experiences into feeling like an "undervalued servant" (Jones, 2004).

Improving strategies to include foster families in decision making and helping foster families develop a realistic understanding of their role in the child welfare and

legal systems will reduce role ambiguity and set up appropriate mutual expectations right from the start. Foster families who continue to struggle against the bureaucracy will become frustrated and burn out much sooner. However, it does take these struggles to create momentum for creating change within the system (Callahan, 2006; Callahan, 2003). The advocacy of foster families has brought this issue forward for child welfare administrators and practitioners to address.

**Living as a public family**

Foster families have the weight of public trust placed on them and are held to a higher standard of parenting than birth parents because of the government's responsibility for the infant (Maedema, 2004; Shlonsky & Berrick, 2001). The public expects that foster families will be able to provide care that is at least a higher standard than the home from which they were removed, and that their care incorporates all the elements of parenting best practice that are accepted within North American society.

However, there are mixed public perceptions with which to cope. Unless there is personal experience with the child welfare system, most members of the public rely on the news and other forms of media to form their impressions of foster care. For example, almost one-third of the public believes that financial reasons are the main motivators for families to begin fostering (Grimm & Darwall, 2005). A study of media portrayal found that a significant portion of the general public has a negative image of foster parents (NCYL). Negative portrayal results in stigmatizing and a significant undercutting of child welfare system recruitment efforts.

**Implications of a resilience framework for foster family recruitment and retention**

Addressing the protective effect that support of foster parents may have on the health and well being of infants will provide guidance for foster family program

enhancement. Although children in foster care spend more time with foster parents than with any other representatives of the health or child welfare system, foster parents often are the least prepared for, and the least supported in, their responsibilities. Few communities have developed programs related to education and support of foster parents caring for infants with prenatal substance-exposure despite the number of infants requiring specialized foster care (Burry, 1999; Zukoski, 1999).

Most of the policy and practice material related to children in care is directed toward toddlers and the older age groups, with little focused content on the infant population. Researchers continue to learn more about the effect of early environments and caregiving on infants and young children. It makes sense then to look at the foster care environment as one likely "location" to find infants with risk factors who would greatly benefit from this type of protective process (from a resilience point of view).

The challenge is to develop services that meet the needs of the primary clients (infants and their foster caregivers), address recent best practice research, meet policy requirements, and are flexible enough to adapt to a range of community situations. A key piece of developing successful programs is to have foster parents participate as collaborators in designing and offering services. Systems of support must not only avoid undermining resilient qualities in families but must also actively nourish those qualities (Patterson, 2002). Development of an understanding of the complexity of the role of foster parent and incorporation of that understanding into plans of care and treatment strategies will ensure the voice of foster parents is represented within decision-making around health and child welfare policies for children-in-care.

The social service system has also historically shouldered the work of supporting foster families by itself. Most of the literature on recruitment and retention focuses on

the role of social service systems in supporting foster parents, but there are also an increasing number of articles that look at how professionals within the health system (pediatricians, public health nurses, early childhood interventionists) and education system (teachers, counselors, special needs assistants) can support foster parents within their work. Some literature is beginning to look at how care of foster children as a special population can be incorporated into evolving roles. For example, the increased use of neonatal and pediatric nurse practitioners or the use of interdisciplinary specialized clinics are ways to provide more holistic health support than the traditional brief visits to the physician's office. Additionally, there is a great deal of health-related information that is infant specific, such as the areas of safety, nutrition, and developmental stimulation. Besides being important for health reasons, this information is important to incorporate into infant care policies from a risk management perspective. For example, if the currently accepted back to sleep position for infants was not used and an infant in care died from Sudden Infant Death Syndrome (SIDS), both foster parents and the child welfare system would be held to that standard of practice.

For infants and children in care who have experienced prenatal substance exposure, including those with Fetal Alcohol Spectrum disorder (FASD), a lifespan approach is recommended to promote stability and attachment (Jones, 2004). Supports may be customized to address the different ages and stages of child development and also the stage of experience of the foster family. For example with older children, child welfare policies and guidelines focus on issues such as management of behavior and support of emotions. With infants, the developmental equivalent is that the focus needs to be on responsiveness of the caregiver to the needs of the infants and the ability of the caregiver to accurately interpret the cues of the infant.

There has been intensive research undertaken at the provincial/state level and the federal level in the past few years on recruitment and retention. Despite clear and consistent recommendations, challenging conditions still persist. For example, MacGregor (2006) found that one strategy to increase retention is to introduce foster parents gradually to the role. However, the reality of the current shortage of foster parents in Canada and the U.S. means that new families are often given too many or too challenging children quickly because there is no where else for the children to go. A 1991 study done by the National Commission on Family Foster Care in the United States found that as many as 60% of foster parents withdrew from the program within the first 12 months citing lack of agency responsiveness, communication and support as primary reasons for leaving. Foster parents have also identified that often the care of the child is the simple part and the complex part of their work is the interaction with the child welfare system. Brown and Calder (2000), in their concept map of the needs of foster parents, identified good relationships with social workers and support from social services as two key concept clusters. In addition to support and communication, foster parents have identified the need for education, respite services and a clear plan for follow-up as key components in preparing to care for an infant with special needs (Barton, 1998; Dozier, Higley, Albus, & Nutter, 2002; Solisay, McCluskey, & Meck, 1994).

**Summary**

The increasing complexity and diversity of the needs of infants and young children coming into foster care result in a requirement for more sophisticated expertise and a strengthened support system for foster parents. Research supports the notion that children with behaviors that are more difficult to manage have an undermining effect on

parental functioning (Linares et al, 1999). A challenge within the foster system is to try to achieve "goodness of fit" between an infant with challenging behaviors and caregivers with the skills and resources to manage care of the infant within their family.

A resilience philosophy applied within a framework of experience specific to the process of foster parents learning how to care for infants with prenatal substance exposure provides an opportunity to develop interventions that support recruitment, retention and satisfaction. Recent trends in the field of child welfare have underscored the importance of examining infants as a unique population (Wulczyn et al., 2002). The large body of knowledge on resilience offers a useful framework for the study of the child welfare experiences of foster families who care for infants who have been exposed prenatally to drugs and alcohol. As infants at risk have considerable potential to overcome or compensate for early stressors, development of multilevel resiliency-focused interventions has the potential to strengthen the protective effects of caregiving excellence within foster families.

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**Table 5-1: Strategies to support foster families at different stages of development.**

| PHASE | EXAMPLES OF RECRUITMENT AND RETENTION STRATEGIES |
|---|---|
| **Phase 1: Preparing to foster** | |
| Triggered to foster | ▪ Use trigger points (such as family history, professional background, personal connection to infant or child) to target recruitment |
| Meeting system requirements | ▪ Provide information ahead of time about the intensity and depth of requirements<br>▪ Provide realistic timeline for completion of these steps |
| Immersing for the first time | ▪ When possible ensure first infant or young child placed in their home does not have acute health or behavior issues.<br>▪ Link to a mentor or experienced foster family to provide support.<br>▪ Frequent visits, phone calls and emails by social worker. |
| Finding niche | ▪ Debrief after each placement or before end of placement to see how the fit was between the characteristics of the infant or child and the family<br>▪ Consider meeting with family to hear from all |

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| | members about how placement went. |
| **Phase 2: Living as a foster family** | |
| Rebalancing family life | ▪ Encourage families to take time to find out what pattern of placement works for them, for example, if they need time between children or if they need to receive another child right away.<br>▪ Examine with family their patterns related to individual time with children, leisure activities, and school activities and discuss how they will adapt these patterns to meet the needs of themselves and the infant.<br>▪ Take the time as a family with each placement to talk about how the infant or child will fit into the family and changes they might expect.<br>▪ Develop additional social network that includes other foster families and respite supports. |
| Honoring limits | ▪ Provide opportunities on an ongoing basis for all members of the family to be comfortable in saying when they have reached limits and need to take a break.<br>▪ All family members can learn the signals that develop in other family members to indicated that they have had enough and need a break or some |

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| | support.<br>▪ Understand that sharing when limits are met is a strength (recognizing capacity) not a weakness. |
| Working the system | ▪ Be honest with families about what is available through the system and what are the limitations of the system.<br>▪ Provide education and support for families not only on providing foster care but also on managing work with the system, including communication, advocacy, developing trust and working relationships with social workers, documentation, and problem solving.<br>▪ Return phone calls and emails promptly.<br>▪ Ensure contracts and payments are organized. |
| Accepting emotional double bind | ▪ Recognize that members of the family may experience feelings of loss and grief when children leave the home.<br>▪ These experiences may look different for each member of the family.<br>▪ Support ongoing communication after placement move with foster child when appropriate<br>▪ Understand that the younger the infant, the more quickly attachment develops with the foster family. |

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| Feeling powerless responsibility | ▪ Strengthen role of foster families within the team that is supporting the foster infant or child.<br>▪ Ensure the input of foster families is taken into account when planning for the infant.<br>▪ Include information on developing roles and relationships of foster family in foster education programs; help families develop realistic expectations of their role in the system. |
| Public parenting | ▪ Work proactively with local media to ensure that fostering is represented positively in the media.<br>▪ Ensure guardianship policies related to family care are realistic in their expectations when compared to specialized homes.<br>▪ Prepare families to manage fostering expectations and on how to present their role in public. |
| **Phase 3: Ending fostering** | |
| Losing fit | ▪ Encourage families to re-evaluate their readiness to foster with major changes or experiences for their family.<br>▪ Include information on this process in fostering education and provide guidance on alternatives to full-time fostering, such as respite. |
| Burning out | ▪ Encourage families to reflect on each placement and |

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| | the effect on their family<br>▪ Encourage families to recognize signs of ongoing and heightening stress and fatigue in members that is not resolving with usual coping and self-care strategies. |
| Transferring child focus. | ▪ Develop exit process that provides future opportunities to reenter fostering.<br>▪ Provide bridging opportunities for families who are interested in continuing to support vulnerable children, ie. respite, medically fragile children program, volunteering roles.<br>▪ Structure recruitment processes to facilitate future return to fostering, particularly for families who are leaving because of developmental changes in situations such as ages of children, moves or employment. |

## GENERAL DISCUSSION AND SUMMARY

The goal of this qualitative research study was to identify the process of becoming a foster family and providing family foster care giving within the context of caring for infants with prenatal drug and alcohol exposure. A constructivist grounded theory approach was used to study foster families (including mothers, fathers, birth and adoptive children) who specialized in caring for infants within a Canadian provincial child welfare system. Participating families represented most of the spectrum of experience, from beginning fostering to developing expertise to ending the formal relationship with the children's ministry.

The research questions asked initially at the beginning of this study addressed the following: What is the basic social process through which foster families integrate the role of caring for infants with prenatal substance exposure into their ongoing family life? What are the conditions that support or hinder integration of this foster family role? The basic social process of *(ad)ministering love* describes how foster families integrate new knowledge, competencies and skills into their role. Conditions that supported or hindered this integration included those at the individual, partner, family, system and community levels.

At the individual level, mothers, fathers, partners and children (as developmentally able) all needed to reflect on their own motivations to foster and their strengths and challenges related to the commitment they needed to make to an infant or young child in their home. At the partner or couple level, the ability of their relationship to flex with changing household and childcare demands was constantly tested. Families needed to consider their ability to invite new and changing members into their family structure and still maintain their own core sense of family. The child welfare system was

heavily influenced by political and public pressures, with these pressures then trickling down to and influencing the work of foster families. Although the provincial child welfare system is intended to be supportive of foster families as a key resource, many embedded components and characteristics of the system are perceived and experienced as stressors and challenges. Communities as an entity were often unaware of the presence of children in need within their boundaries and the foster families that cared for them. From a community or society perspective the primary reason for children being in care is still ultimately poverty, and resources and supports for families in need are often not sufficient to sustain their well being.

This theoretical framework was developed to explain and account for well-functioning family foster homes that care for infants with prenatal substance exposure. The framework serves as a basis for improved practice, policy development, education and training, research and evaluation. Information from this study will be useful for those interested in strengthening the system of foster care for the infant population, including health and social service providers who support infants and foster families, policy makers, particularly within the child welfare system, and foster families themselves. The framework may also have application to other foster child populations and other caregiving populations such as children with special needs, family members including the elderly, chronically ill, or disabled.

***Implications for nursing practice***

Over the past twenty years, as perinatal substance use has emerged as a significant health and social issue, health and social service providers have come together to plan and deliver services in a more collaborative manner. However, unless formal institutional connections and links are in place between child welfare agencies

and health care systems, there is often only limited sustained cross-discipline work that occurs in relation to the support of foster families and infants and children in foster care. Dicker, Gordon and Knitzer (2001) state that there has been little attention focused on linking child welfare practice with health care, early intervention and other strategies that hold potential for addressing the multiple health and social risk facing infants and children in foster care. Their position paper on improving the healthy development of young children in foster care is introduced as a "wake up call" to challenge communities to pay more attention to the needs of this population. They identify five strategies to promote the healthy development of young children in foster care:

- Provide developmentally appropriate health care to young children in the context of comprehensive health care for all foster children
- Design and implement specialized developmental and mental health assessments and services for young children in foster care
- Create monitoring and tracking mechanisms to ensure needed health, developmental, and mental health services are provided
- Ensure that young children in foster care have access to quality early care and learning experiences
- Use the oversight authority of the courts to ensure that children in foster care receive needed health, developmental, and mental health services as a part of permanency planning.

A number of professional and organizational standards are now available to support strategies such as these (AAP, 2000; AAP, 2002).

Health professionals such as registered nurses, physicians, child and infant development workers/therapists interface with infants and young children from foster

care in a number of places, including hospital maternity units and nurseries, public health clinics, parenting groups, immunization clinics, follow up clinics, therapy programs, and schools. However, they have fewer opportunities to network with foster families and social workers on a regular basis. There are many opportunities to strengthen this connection and plan collaboratively to support successful parenting and healthy outcomes of children in care.

This infant foster care model provides a deeper context for gaining an appreciation of the daily and continuing work and commitment of foster families, beyond the understanding we may have that is built on media and anecdotal impressions. Knowing that the work of being a successful foster family is much greater than simply understanding more about the infant's health issues provides a number of opportunities to support the health of foster families, and as a result, the health of children in their care. Strategies for health professionals to support foster families include:

- Working with families to understand the effect of children moving in and out of their core family on each member of the family and the family as a whole.
- Partnering with child welfare to offer education and support opportunities for foster families.
- Developing strategies to track the health of children who move in and out of foster care and reduce incidence of loss of contact.
- Developing health promotion opportunities for foster children and foster families.
- Providing health advice to social workers that are planning foster care placements for children with specific health needs.

***Implications for nursing education***

Nursing curriculum traditionally has included a number of perinatal, pediatric, family and public heath courses. Information is usually taught on topics such as family development, parenting role acquisition, adaptation to parenthood, and grief and loss. In more recent years curriculum has broadened to encourage nursing students to consider and be sensitive to a wide range of family compositions, such as single parent families, gay or lesbian parents, adolescent parents, and families of different cultures. Opportunities exist at these points to introduce the concept of foster families and their unique needs. Within the direction of primary care, there also may be graduate education opportunities, such as with nurse practitioners for foster child health clinics.

With the emerging trend in interdisciplinary education, it is also important to think beyond the borders of nursing and health care. For example, in addition to cross-program education with groups such as physicians and nurses, it would be useful to consider cross-program initiatives with faculties of nursing, child and youth care and social work.

***Implications for nursing research***

The fields of intervention research with infants and children with prenatal substance exposure and foster family well being are at present still underdeveloped and there is great opportunity to collaborate with child welfare research partners to explore issues of family health (such as relationship maintenance, sibling adaptation, lifestyle changes) and effective infant caregiving strategies (such as feeding, settling, sleeping, attachment). There are also opportunities to examine policy and systems functioning in relation to foster family well being (such as effectiveness of recruitment and retention strategies, financial compensation, team inclusion).

As discussed in Paper 4 this model or components of this model may be applicable to other groups such as foster families of older children, families of children with disabilities and kin caregivers. For example the notion of honoring limits has cross-over appeal to other ages groups and caregiver groups. In addition to the overall model, each core concept itself would be a rich area to further explore. A potential area of study would be to apply an infant lens and the concepts within this model to the 12 domains of foster care competency recently identified by Buehler et al. (2006).

***Summary***

Foster families are in general an underacknowledged population within our communities yet responsible for infants and children with increasingly complex health and social issues. Silver, Amster and Haecker (1999) challenge that the key to improving outcomes for infants and children in foster are is to strengthen collaboration and partnership between the individuals and agencies involved in their care and support. Foster families are one of the key groups of individuals involved and as such should be provided with opportunities to play a role in future planning for infants and children in their care.

The issues of recruitment, retention and satisfaction are intertwined and all need to be present in a comprehensive planning model for developing and sustaining quality specialized foster care for infants and children with special needs. A multilevel initiative will include strategies at the individual, family, system and community levels. Including foster families in this planning will contribute to the development of more meaningful strategies that will have greater potential for success. Ultimately, development and support of skilled and loving foster families is one of the most effective interventions available for promoting positive development of infants in foster care.

## APPENDIX A

## INITIAL INTERVIEW QUESTIONS

### TIME PERIOD 1: PRIOR TO BEGINNING FOSTERING

These are the initial questions for the interview. The questions may change as the study progresses depending on the concepts and/or categories that the participants identify.

- Tell me about how your family became interested in becoming a foster family.

  Probe: Please share with me the kinds of things your family talked about as you were making the decision to start fostering.

  Probe: What did you see as the benefits you would receive from fostering?

  Probe: What kinds of things were you worried about before beginning to foster?

- Tell me about what kind of expectations or impressions you have about what fostering is going to be like.
- What was the home study and orientation experience like for your family?
- Is there anything you want to add or ask about before we finish the interview?

## APPENDIX B

## DRAFT INTERVIEW QUESTIONS

## TIME PERIOD 2: WITHIN THE FIRST YEAR OF BEGINNING FOSTERING

These are the initial questions for the interview. The questions may change as the study progresses depending on the concepts and/or categories that the participants identify.

- Tell me about how your family became interested in becoming a foster family.

  Probe: What did you see as the benefits you would receive from fostering?

  Probe: What kinds of things were you worried about before beginning to foster?

  Probe: Tell me about what kinds of expectations or impressions you had before you started about what fostering was going to be like.

  Probe: What did you see as the benefits you would receive from fostering?

  Probe: What kinds of things were you worried about before beginning to foster?

  Probe: Tell me about what kinds of expectations or impressions you had before you started about what fostering was going to be like.

- Could each of you tell me about how this year of being a foster family has gone for you and how you think it has been for your family?

  Probe: Does it compare in any way to your expectations? How so/not?

  Probe: What have you found the most helpful as your family has been taking on this role?

  Probe: What have you found frustrating or the least helpful during this time?

  Probe: How comfortable is your family feeling with fostering compared to when you first started?

- Is there anything you want to add or ask about before we finish the interview?

## APPENDIX C

## DRAFT INTERVIEW QUESTIONS

### TIME PERIOD 3: AT LEAST THREE YEARS OF FOSTERING EXPERIENCE

These are the initial questions for the interview. The questions may change as the study progresses depending on the concepts and/or categories that the participants identify.

- Tell me about how your family became interested in becoming a foster family.
- Share with me the kinds of things your family talked about as you were making the decision to start fostering.

  Probe: What did you see as the benefits you would receive from fostering?

  Probe: What kinds of things were you worried about before beginning to foster?

  Probe: Tell me about what kinds of expectations or impressions you had before you started about what fostering was going to be like.
- Could each of you tell me about how being a foster family has gone for you and how you think it has been for your family? What has it been like "along the way"?

  Probe: Does it compare in any way to your expectations? How so/not?

  Probe: What have you found the most helpful as your family has been taking on this role?

  Probe: What have you found frustrating or the least helpful during this time?

  Probe: How comfortable is your family feeling with fostering now as compared to when you first started?
- How has your family changed because of the experience of fostering?
- Is there anything you want to add or ask about before we finish the interview?

## APPENDIX D

## DRAFT INTERVIEW QUESTIONS

## RESOURCE WORKERS

These are the initial questions for the interview. The questions may change as the study progresses depending on the concepts and/or categories that the participants identify.

1. Describe for me your role in supporting foster families.
2. In your experience, as a foster family gains experience and skill, how does the process usually go for them?
3. Have you noticed any common characteristics in families that do well/don't do well in taking on the role of fostering? What are they?
4. How do you find foster families experience the systems end of things?

## APPENDIX E

## LETTER OF INFORMATION FOR THE FOSTER FAMILY

### RESEARCH TEAM MEMBERS:

Lenora Marcellus, RN, MN, PhD student
Faculty of Nursing
University of Alberta
(250) 391-1913
lenora@ualberta.ca

Dr. Jane Drummond (supervisor)
Professor, Faculty of Nursing
University of Alberta
(780) 492-6410
jane.drummond@ualberta.ca

I am asking foster families who look after infants to take part in this study. One purpose of this study is to learn more about how families become interested in fostering and become good at looking after infants. A second purpose is to find out what helps them in doing this. I hope that the results of this study will help improve services and supports for foster families who care for infants. This study is my PhD research project through the University of Alberta. MCFD has agreed to me doing this study, but it does not control or fund the study in any way.

Taking part in this research study is up to you and your family. Here is some basic information about the study. Take your time reading this information letter. Please phone or email me if you have any questions or need more information. Thank you for thinking about taking part in this study.

### Name of research study:

The process of role development in foster families caring for infants with prenatal substance exposure.

### Procedure:

I am looking for about 15 to 20 families for this study. Each family will take part in one or two audio-taped interviews. The interviews will be at a time and place that works for you. The interviews will take place sometime between January 2005 and June 2006. During these interviews, I will ask you to talk about your experiences of becoming a foster family. For this study, it is important that everyone in the family is willing to participate. Personal information in your MCFD files will **not** be part of the study.

**Benefits and/or risks:**

The results of this project may help improve supports and services for foster families. Also, taking part in a family interview may be a chance to think back about your experiences of fostering.

There may be some small bother for you in being telephoned and interviewed. There is little or no risk likely for the families who agree to take part. If the interview causes any stress or concern for your family, I will connect you with foster parent support services.

During the interviews, something may be said by one person that is not comfortable for another person. Before starting the interview, I will talk about privacy. I will also talk about every family member having the same chance to talk and everyone being treated with respect.

**Privacy and confidentiality:**

I will hold all information confidential (or private), except when professional codes of ethics or legislation (or the law) requires reporting. The information you give will be kept for at least five years after the study is done. The information will be kept in a safe area (a locked filing cabinet and a password protected computer file). Your name or any other information that identifies you will not be attached to the information you give. Your name will also never be used in any presentations or publications of the study results. I will be the only person to hear the audiotapes.

I will be sharing my work in this study with my professors and with members of a research group at the University of Victoria. No names will be attached to the work.

The information gathered for this study may be looked at again sometime in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Before the interview starts, I will remind the family that what is said needs to remain confidential. Because this study involves family interviews, complete confidentiality cannot be assured.

**Freedom to take part in or not take part in the study:**

Taking part in this study is up to your family. If you are interested, I will visit your family and talk about the study and its purpose. I will also talk about what is expected of your family and any possible risks to you. After this visit, it is still up to your family if you want to take part. I would like to get consent (saying yes to take part) from all members of the family.

Nobody from MCFD will know whether or not you take part. There is no risk to you if you do not want to take part in this study. You have the right to stop being in the study at any time without problem. If you want to stop part way through the study, your data will not be used further.

**Right to not answer a question:**

You have the right to answer only the questions you are comfortable answering. I have included a list of the main interview questions with this information letter. Before starting the interview, I will let you know again about your right to not answer a question.

**The sharing of results:**

The results will be shared in several ways:

- Articles in magazines
- Talks at workshops
- Research report placed in the University of Alberta library
- Research report given to foster parent, health, and social service groups
- Newsletter to all families that were interviewed and other foster families looking after infants

**In case of concerns:**

If you have any concerns about any part of the study, please call Dr. Joanne Olson at 1-780-492-4338.

**Initials:**

_____

Family members

_____

Student – Lenora Marcellus

## APPENDIX E

### Letter of information for the resource workers

**RESEARCH TEAM MEMBERS:**

Lenora Marcellus, RN, MN, PhD student
Faculty of Nursing
University of Alberta

UNIVERSITY OF ALBERTA

(250) 391-1913
smarcellus@telus.net

Dr. Jane Drummond (supervisor)
Professor, Faculty of Nursing
University of Alberta
(780) 492-6410
jane.drummond@ualberta.ca

**LETTER OF INFORMATION**

**(For resource social workers)**

I am seeking foster families who care for infants to participate in this research study. The purpose of the study is to learn about the process of: a) how families become interested in becoming foster families, b) how they become expert in caring for infants with prenatal substance exposure, and c) factors that influenced their ability in doing this. This study is my dissertation research project through the University of Alberta. The Ministry of Child and Family Development has given its consent, but it does not control or fund the study in any way.

I hope that the results of this study will guide further development of services and supports for foster families who care for infants with prenatal substance exposure.

Participation in this research study is completely voluntary. Here is some basic information about the study. Take your time reading the material and please feel free to

contact me directly if you have any questions or need more information. Thank you in advance for considering participating in this study.

**Title of research study:**

The process of role development in foster families caring for infants with prenatal substance exposure.

**Procedure:**

I am looking for approximately 3 resource social workers to interview for this study. Each resource worker will participate in one or two face-to-face audio-taped interviews at a time and location that is convenient for you. The interviews will take place sometime between January and June 2005. During these interviews, I will encourage you to talk about your experiences of supporting foster families who care for infants with prenatal substance exposure. I have included a sample of interview questions that you may be asked with this information package.

**Benefits and/or risks:**

This research project has the ultimate potential to improve supports and services for present and future foster families. In addition, the process of participating in an interview may provide an opportunity for you to reflect on your experiences with foster families.

There may be some minor inconvenience for you in being telephoned and/or interviewed. You have been informed about the time commitments in this letter and the attached consent form. There is no risk associated with declining to participate in this study. There is minimum risk anticipated for the participants who agree to participate. All participation is completely voluntary and you may end your involvement with the study at any time.

I would like to remind you that MCFD has no control over this study, and thus your participation is voluntary. Participation in this study is not a part of job performance, it will in no way impact your employment, and the information you share will remain confidential.

**Privacy and confidentiality:**

I will hold all information confidential (or private), except when professional codes of ethics or legislation (or the law) requires reporting. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (a locked filing cabinet and a password protected computer file). Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results. Only quotes without identifying information will be used in the data analysis

and discussion. Only the principle applicant and the co-applicant will hear the audiotapes.

No other agencies or individuals will have access to this confidential data now or in the future. I will be discussing data analysis with my research committee and with members of the Grounded Theory Club at the University of Victoria, but no names or identifiers will be attached to that data. It is possible that I may look at the information gathered for this study again sometime in the future to help answer other study questions. If this happens, the ethics board will first review the study to ensure the information is used ethically.

**Freedom to participate in or withdraw from the study:**

Participation in this study is voluntary. For those of you who are interested in learning about the study, I will present the study, its purpose, what is expected of participants, and any potential risks to participants. I will clearly convey to you that participation is voluntary, and that individual feelings of obligation toward BC MCFD or toward myself should not influence the decision to participate. Receiving more information is in no way intended to coerce participation. I will inform you that your agreeing to or declining to participate will in no way affect your working relationship with BC MCFD and that no one from BC MCFD will know if you decline participation.

You have the right to withdraw at any time without consequences. You will be offered continued opportunities to decide whether or not to continue to participate. If you wish to withdraw part way through the study, your data will be removed.

**Right to refuse to answer a question:**

You have the right to answer only the questions you are comfortable answering. I will provide you with a list of the interview questions so that you will have a general idea about the nature of the interview. Prior to the beginning of the interview, I will remind you again about your right to refuse to answer a question.

**The sharing of results:**

Results of the study will be shared in both written and oral formats. The findings will be shared in the following ways:

- Papers will be submitted to both scholarly and practice-based journals and newsletters.
- Presentations will be made at conferences for both professionals and foster parent associations.
- A copy of the dissertation (doctoral research) will be placed in the University of Alberta library
- A copy of the final summary report will be given to the British Columbia Foster Parent Association, MCFD, and the Vancouver Island Health Authority.

- The findings will be presented at my dissertation oral defense, as a requirement for the PhD Degree in Nursing
- A newsletter with the findings will be mailed to all members on the Safe Babies foster parent mailing list.

**Additional contact:**

If you have any concerns about any aspect of the study, please call Dr. Joanne Olson at 1-780-492-4338.

**Initials:**

_____
Participant

_____
Researcher

## APPENDIX G

### CONSENT FOR INTERVIEW AND AUDIOTAPING
**(For members of the foster family)**

I am being invited to take part in a study called *"The role development of foster families caring for infants with prenatal substance exposure"*, done by the graduate student, Lenora Marcellus, as part of the requirements for a PhD in Nursing degree from the University of Alberta.

The purpose of this study is to find out more about the process of: a) how families become interested in becoming foster parents, b) how they become experts in caring for infants with prenatal substance exposure, and c) what ways they are helped in doing this.

I understand that this study will be useful by discovering the ways in which foster parents are supported or not supported in providing care.

| **Title of Project**<br><br>**The process of role development for foster families caring for infants with prenatal substance exposure**<br><br>**Part 1: Researcher Information** | | |
|---|---|---|
| Name of Principal Investigator: Dr. Jane Drummond<br>Affiliation: Professor, Faculty of Nursing, University of Alberta<br>Contact Information: jane.drummond@ualberta.ca | | |
| Name of Co-Investigator/Supervisor: Lenora Marcellus<br>Affiliation: PhD student, Faculty of Nursing, University of Alberta<br>Contact Information: smarcellus@telus.net | | |
| **Part 2: Consent of Subject** | | |
| | **Yes** | **No** |
| Do you understand that you have been asked to be in a research study? | | |
| Have you read and received a copy of the attached information sheet? | | |
| Do you understand the benefits and risks involved in taking part in this research study? | | |
| Have you had an opportunity to ask questions and discuss the study? | | |
| Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care. | | |

| | | |
|---|---|---|
| Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information? | | |

**Part 3: Signatures**

This study was explained to me by:

_____

Date: _____

*I agree to take part in this study.*

Signature of Research Participant:

_____

Printed Name:

_____

Witness (if available):

_____

Printed Name:

_____

**I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.**

Researcher:

_____

Printed Name:

_____

* A copy of this consent form must be given to the subject.

## APPENDIX H

### CHILD ASSENT FORM

This letter is about a research project. I am a nurse who is interested in finding out more about foster families. I am asking if you are willing to have me come to your home to visit with you and your family. During the visit we would talk all together about what it is like to be in a foster family and care for the babies and children that come to stay with you for a while.

If you and your family agree to be in this study, I will come to your house and visit for about one or two hours. I will use a tape recorder so that I don't forget all the things your family says. I will ask a few questions but mostly I will listen to what you and your family have to say. I will keep all the information from your family private.

You can ask me any questions that you have about this study. If you have a question later that you didn't think of now, you can ask me next time.

Signing here means that you have read this paper or had it read to you and that you are willing to be in this study. If you don't want to be in this study, don't sign. You can also change your mind later and not be in the study. Being in this study is totally up to you and your family, and no one will be mad at you if you don't want to do it.

If you want to be in the study sign here: _____
Date: _____

Signature of researcher: _____
Date: _____

Signature of parent: _____
Date: _____

**APPENDIX I**

**CONSENT FORM FOR RESOURCE WORKERS**

UNIVERSITY OF ALBERTA

**CONSENT FOR INTERVIEW AND AUDIOTAPING**
**(For social workers)**

I am being invited to take part in a study called "*The role development of foster families caring for infants with prenatal substance exposure*", done by the graduate student, Lenora Marcellus, as part of the requirements for a PhD in Nursing degree from the University of Alberta.

The purpose of this study is to find out more about the process of: a) how families become interested in becoming foster parents, b) how they become experts in caring for infants with prenatal substance exposure, and c) what ways they are helped in doing this.

I understand that this study will be useful by discovering the ways in which foster parents are supported or not supported in providing care.

| **Title of Project**<br><br>**The process of role development for foster families caring for infants with prenatal substance exposure**<br><br>**Part 1: Researcher Information** |
|---|
| Name of Principal Investigator: Dr. Jane Drummond<br>Affiliation: Professor, Faculty of Nursing, University of Alberta<br>Contact Information: jane.drummond@ualberta.ca |

| Name of Co-Investigator/Supervisor: Lenora Marcellus<br>Affiliation: PhD student, Faculty of Nursing, University of Alberta<br>Contact Information: smarcellus@telus.net | | |
|---|---|---|
| **Part 2: Consent of Subject** | | |
| | **Yes** | **No** |
| Do you understand that you have been asked to be in a research study? | | |
| Have you read and received a copy of the attached information sheet? | | |
| Do you understand the benefits and risks involved in taking part in this research study? | | |
| Have you had an opportunity to ask questions and discuss the study? | | |
| Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care. | | |
| Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information? | | |
| **Part 3: Signatures** | | |
| This study was explained to me by:<br>_____<br>Date:<br>_____ | | |
| *I agree to take part in this study.*<br>Signature of Research Participant:<br>_____<br>Printed Name:<br>_____ | | |
| Witness (if available):<br>_____<br>Printed Name:<br>_____ | | |

**I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.**

Researcher:

_____

Printed Name:

_____

* A copy of this consent form must be given to the subject.

## APPENDIX J

## RECRUITMENT CRITERIA FOR PARTICIPATION

**General criteria:**

- Residents of Vancouver Island
- English speaking
- Family to include parent(s) and at least one biological child able to contribute to knowledge of the fostering experience (approximately 10 years of age or older)
- Approved to foster parent with the British Columbia Ministry of Child and Family Development
- Have been designated as a specialized infant foster home for infants with prenatal substance exposure
- Have completed the Safe Babies training program

**Additional time period 1 criteria:**

- Have not yet had a foster child placement in their home

**Additional time 2 criteria:**

- Family is within first year of having their first placement

**Additional time 3 criteria:**

- Family has fostered for at least three years

BRITISH
COLUMBIA

January 18, 2005

University of Alberta
114 St - 89 Ave Edmonton
ALB T6G 2EI

**Attention: University Ethics Committee**

As Director under the *Family Child and Community Services -4ct,* I would like to offer my support and permission for Lenora Marcellus to complete her research project with the Safe Babies Program on Vancouver Island.

I understand that the study will be forwarded to the University Ethics Committee and I look forward to reviewing the results of the Committee and the ongoing work.

**Sincerely,**

Tom Weber
Director of Child Welfare
Vancouver Island Region

PC: Lenora Marcellus
Jane Cowell
RED, Vancouver Island Region

Ministry of Children and Family | Vancouver Island Region | Stn. Prov. Gov't PO Box 9727 | Telephone: (250) 952-4780